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**AN EXPLORATION OF COMFORT  
AND DISCOMFORT AMONGST  
CHILDREN AND YOUNG PEOPLE  
WITH SEVERE PHYSICAL,  
LEARNING AND COMMUNICATION  
DIFFICULTIES WHO DEPEND ON  
POSTURAL MANAGEMENT  
EQUIPMENT**

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PhD

2013

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**ELIZABETH ANNE LYONS**

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of the requirements of the University of  
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Studies

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## **ABSTRACT**

The natural response to the intrusive bodily sensation of discomfort is positional change. The purpose of this study was to explore how children and young people with profound physical, learning and communication difficulties, largely dependent on others to gauge their need for positional change, have their comfort needs met when using postural management equipment.

Thirteen qualitative case studies were undertaken. Nine of the participants attended a special needs education primary or secondary school, two were in transition to school and two attended day services. All participants had a neurodevelopmental disability, with each being the focus of one case study. Parents, teachers, therapists and key support staff were interviewed, and the school or day centre routines of the children and young people were observed, with selective video recording. Single case and cross case analyses were undertaken.

The findings showed threats to comfort include the restrictive nature of various accessories, hastiness of care tasks producing positioning errors and the procedural stretching of tissues prior to application. Opportunities for lessening discomfort included scheduled daily routines and time out of postural management equipment. Equipment use for the children and young people in this study was intrinsically coupled with care giving. Attentive caregivers read the behavioural expressions of the children and young people and reassuringly responded, safeguarding them from discomforting experiences. This maximised each individual's adaptive functioning, without compromising the benefits of postural support.

This study highlights that the same item of equipment can be both comfortable and uncomfortable. Given the social and interactional world in which the children and young people live and learn, and the complex nature of their difficulties, it is others who must accept responsibility for ensuring their optimal level of comfort.

## ACKNOWLEDGEMENTS

I wish to express sincere appreciation to my supervisors, Dr Anna Jones, Dr Veronica Swallow and Dr Colin Chandler. They have motivated me at every stage and I thank them for their ongoing encouragement, for constructive comments on my drafts and their combined wisdom, but above all their unfailing belief in my ability to complete this study.

It has been a great pleasure to work with the children, young people, parents, teachers, teaching support assistants and therapists. This study would not have been possible without you and I owe a depth of gratitude to you all.

I dedicate this work to the children, young people and families I have had the privilege of working with during my career, my parents and family.

## Declaration

I declare that the work contained in this thesis has not been submitted for any other award and that it is all my own work. I also confirm that this work fully acknowledges opinions, ideas and contributions for the work of others.

Ethical clearance for the research presented in this thesis has been approved. Approval has been sought and granted by the School Ethics Committee and a National Health Service Local Research Ethics Committee on 25<sup>th</sup> November, 2005.

Name: Elizabeth Anne Lyons

Signature:

Date:

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## LIST OF ABBREVIATIONS USED IN THE THESIS

BES	British Engineering Society
CP	Cerebral Palsy
CAQDAS	Computer- Assisted Qualitative Data Analysis Software
COREC	Central Office of Research Ethics Committee
CSED	Care Services Efficiency Delivery
CRB	Criminal Record Bureau
ECM	Every Child Matters
DfE	Great Britain Department for Education
DfEE	Great Britain Department for Education and Employment
DCSF	Great Britain Department for Children, Schools and Families
DfES	Great Britain Department for Education and Skills
DoH	Great Britain Great Britain Department of Health
GMFCS	Gross Motor Function Classification System
ICF	International Classification of Functioning
ICF-CY	International Classification of Functioning- Child and Youth
LEA	Local Education Authority
LREC	Local Research Ethics Committee
MRCE	Medical Research Council Ethics
NCCPC	Non-Communicating Children's Pain Checklist
NHS	National Health Service
NPSA	National Patient Safety Agency
NRES	National Research Ethics Service
PMLD	Profound and Multiple Learning Difficulties
PEG	Percutaneous Endoscopic Gastrostomy
PPP	Paediatric Pain Profile
QCA	Qualification and Curriculum Authority
REC	Research Ethics Committee
SEN	Special Educational Needs
SLD	Severe Learning Difficulty
SMA	Spinal Muscular Atrophy
UEC	University Ethics Committee
WHO	World Health Organisation

## LIST OF TERMS USED IN THE THESIS

Adaptive seating	The custom prescription and application of sitting support devices based on therapeutic principles (Roxborough 1995).
Analytic induction	A way of building explanations in qualitative analysis by constructing a set of causal links between events, actions etc. in one case and the iterative extension of this to further cases (Gibbs, 2002)
Attribute	A property of a case, node or document
Coding	Involves attaching one or more keywords to a text statement in order to permit later identification of a statement , where as categorization entails a more systematic conceptualization of a statement
Coding on	The process of reviewing and recoding the text already coded at a node This means reducing or expanding the coded text to reflect the refinement of the concept the node represents
Concept	A mental interpretation generalized from instances
Dissimulation	Concealment or disguising a pain
Emic perspective	Insider's perspective on reality
Epistemology	Is a philosophical concept that is concerned with the constitution of knowledge and the processes of generation
Empiricism	A school of thought claiming that experience via the senses is the source all knowledge. It is characteristic of positivism generally (Robson,2002)
Etic perspective	External, social scientific perspective on reality
Experiential knowing	To know something by experiencing it
Facticity	The word fact could be substituted, but the factuality of a fact is what Heidegger terms Dasein's facticity. This kind of fact has quite a different ontology from the factual occurrence of something.
Generalization	Applying a statement to many or all cases
GMFCS:	Gross Motor Function Classification System: This is intended to be used as a quick and easy classification based on a child' self initiated movement with emphasis on sitting and walking, primarily for use with children with cerebral palsy. Five levels, Levels I-V, with children at level V severely limited
Interpretive	Relies on human reasoning and judgement
Intensive Interaction.	An approach to enhancing the communication and social abilities of people with profound intellectual disabilities using



	principles from caregiver—infant
Pre-intentional communicators	Functioning pre-linguistically, not using symbols in the interactive opportunities
Postural Management	A postural management programme is a planned approach encompassing all activities and interventions, which affect an individual's posture and function. Programmes are tailored specifically for each child and may include special seating ,night time support, standing supports, active exercise, orthotics , surgical interventions, and individual therapy sessions (Gerricke, 2006)
Member checking	Asking a data source to confirm researcher reporting
Multiple realities	Alternative perspectives
Model	A diagram in which elements that can represent nodes , documents or simply ideas are linked with lines and arrow which show how they relate to each other
Naturalistic research	Observation of ordinary happenings in their own places
Naturalistic generalization	Knowledge from direct experience
Non-symbolic	Pre-intentional or intentional idiosyncratic or personalized behaviours judged to be communicative (Foreman <i>et al.</i> , 2007)
Ontology	A philosophical idea concerned with the nature of the social world what ls comprises and the object within it and relationships between those objects
Humanistic	A term with many, widely different meanings. Here used to refer to disciplines and approaches where a scientific approach is considered inappropriate (Robson, 2002)
P-level attainment targets	Pupils work below level 1 of the national curriculum(QCA, 2009)
Professional craft knowledge	Knowledge derived from practical experience
Severe Learning Difficulty	Pupils with severe learning difficulties have significant intellectual or cognitive impairments. This has a major effect on their ability to participate in the school curriculum without support. They may also have difficulties in mobility and coordination, communication, perception, and the acquisition of self-help skills. Pupils with severe learning difficulties will need support in all areas of the curriculum. They may also require teaching of self-help, independence and social skills. Some pupils may use sign and symbols but most will be able to hold simple conversations. Their attainments may be within the upper

P scale range (P4-P8) for much of their school careers (that is below level 1 of the National Curriculum).

Special seating	Alternative term for adaptive seating. Special seating is that component of a seating system (wheelchair or static), which is specifically adapted for the child, to accommodate or control postural difficulties (British Society of Rehabilitative Medicine 2004)
Substantive	Pertaining to the subject matter or content
Symbolic communication	A communication that represents a shared meaning, an object experience or message in the present context ( e.g. a manual sign or visual symbol (Foreman, <i>et al.</i> , 2007)
Tacit knowledge	Knowledge embedded in practice
Teaching Assistant	A referred to as classroom assistant, learning support assistant or special needs assistant. In the thesis I use teaching assistant
Vignette	A vignette is a focussed description of a series of events taken to be representative, typical or emblematic in the case (Miles and Huberman, 1994, p.81)

# CHAPTER 1

## INTRODUCTION

### **The starting point**

Are you sitting comfortably? (Concise Oxford Dictionary of Quotations, 2006)

A familiar phrase, most of us have probably experienced discomfort from sitting in one position too long. Noticeable is our response, an increase in fidgety movements; eventually opportunity to move is forthcoming. This short illustration sets the scene for this research, but as an experience of children and young people with severe physical learning and communication difficulties who use adaptive seating and other items of postural management equipment. The starting point of this research came about following a significant event in my clinical career; a father, who felt his child was uncomfortable and inhumanely strapped into his wheelchair, expressed some damning words. These words, communicated at a multidisciplinary postural management and seating clinic, were influential and resulted in an emergent purpose for the study, that of gaining a greater understanding of adaptive equipment comfort and discomfort with this specific group of children and young people.

School based therapists are health care practitioners who often initiate equipment provision. However, children and young people with multiple and complex needs often require the combined efforts of parents, teachers, therapists and other multi-agency team members to help them overcome a number of difficulties at home and school. My involvement with children with physical disabilities dates from 1976 when I first worked as a physiotherapist in three special schools. This was a decade of change; children with profound learning difficulties had only just acquired legislative entitlement to such learning environments.

Interest in comfort and discomfort was not immediately translated into this current research as the ethical implications of undertaking research with a group of children and young people unable to give consent to participate at first seemed overwhelming. As a physiotherapist, I have been at the forefront of early service development in the field of postural management, involved in a number of equipment evaluations, and have an enduring interest in adaptive seating and wheelchair provision for children and young people. Consequently, I have a personal drive to find out what happens in the real world of equipment use and to provide findings that could improve professional understanding of child and family need. In an earlier project I had used a phenomenological approach to investigate posture, seating and wheelchair use in

persons with multiple sclerosis; comfort was a theme which evolved from the data, seating discomfort was real (Lyons, 1999). I found myself becoming more and more focused on this topic and possible implications for those who struggle to communicate the presence of intrusive bodily sensations. The desire to explore further led to the current study

## **Formulation of research questions**

A starting point in the formulation of the research questions was consideration of a potential discomfort state existing because of an extended period of equipment use, such as occurs in the sedentary worker. Positional change is the natural response to intrusive bodily sensations of discomfort, but in the population of children and young people who are unable to move independently, this natural phenomenon becomes complex and alarming for two reasons. Firstly, those with profound learning difficulties may be unable to communicate an experienced discomfort verbally. This raises the possibility that caregivers and professionals may fail to recognize and thereby respond to the discomfort cues. Consequently, a positional change may not be forthcoming. Secondly, these children and young people by virtue of their physical disabilities are more likely to display some of the characteristic body function disturbances known to produce an alteration in body biomechanics and localized physiological responses allied to bodily discomfort. A review of the literature revealed some noteworthy exploration of these concepts but little about the situational comfort needs of persons who do not use language.

Children and young people with repositioning needs are reliant on parents, professionals and support workers who on a daily basis interpret and ascribe meaning to levels of comfort and discomfort. Of necessity these significant others<sup>1</sup> have a critical role as respondents in this research. Yet a point difficult to dismiss is ownership of the comfort/discomfort experience. Such experience belongs to the child or young person, is unique to them and, like the population of sedentary workers, they ought to have their comfort needs met. This research embraced an implicit aim, that of giving a 'voice' to the comfort/discomfort experiences of these children and young people, as a result of using postural management equipment.

I made a number of assumptions with regard to the dearth of literature, but one in particular was the complexity of undertaking ethical research with a population often classed as vulnerable. Partly derived from an insider perspective, there was also an

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<sup>1</sup> The term significant others is used when I collectively refer to parents, teachers, teaching assistants, key workers, therapists

implicit assumption, on my part, that advancement of knowledge was possible if a person-centred, ethical methodology could make the tenuous constructs overt. A discomfort experience may in part be biologically determined but the child or young person, as an individual, has grown, developed and lives in a social world, and the methodology would have to acknowledge the embodied child or young person. This was to be the first of many challenges. Conventional methods widely used for intensity, comfort and discomfort assessment of seating, for example rating scale techniques, would not be possible. Such measures infer the person will be able to verbalize their discomfort. The findings from a preliminary phase where I talked to children who used adaptive seating, alongside assertions made in other disciplines about the complexity of these constructs, substantiated the decision to utilize a case study exploratory methodology within everyday environments of equipment use. This in the words of Alderman *et al.* (1980) would allow data to be 'strong in reality' (Bassey, 1999, p.23). On commencement of the main study early reflection led to a refocus of the research questions, placing less emphasis on duration and more on the influences affecting use. Readings during this time continued to influence the developing methodology.

With the purpose of giving account of comfort and discomfort as experienced by a group of children and young people with severe physical, learning and communication difficulties when using adaptive seating and other items of positioning equipment, four questions guided the inquiry.

- How does the child or young person communicate the experience allied to positional comfort or discomfort?
- What are the antecedent factors and attributes of equipment comfort and discomfort?
- How do these relate to duration of equipment use?
- How do others who are part of the social life world of the child / young person interpret comfort and discomfort?

The topic became visible because of my work in the past. These research questions, the methodology and subsequent findings represent a journey of exploration into terrain initially portrayed as familiar into the unknown where challenge came from once seemingly recognizable concepts.

I will discuss the ethics of privacy in chapter 6 but point out that I have used pseudonyms throughout to protect the anonymity and confidentiality of study participants, for the same reason I have refrained from naming any schools or day services involved in this study.

## **Flow of the thesis**

The thesis I have divided into twelve chapters numbered sequentially throughout. Chapters 1 to 2 introduce and use literature to contextualise the research. Chapters 4 to 7 map development of, and then describe implementation of method. Chapters 8 to 10 present the findings, with interpretation alongside existing theory discussed in chapter 10. Chapter 11 provides a critical self-appraisal of the research, and chapter 12, the final chapter, concludes the study in terms of its main findings and limitations, whilst identifying scope for future research. A summary of each chapter occupies the remainder of this chapter.

Chapter 2 is the starting point of an introduction to the children and young people, who use adaptive equipment, locating them with their physical, learning and communication difficulties in the environments where they live, learn and experience life. A challenge to interpretation of subjective experience exists because of these difficulties, but collaborative partnerships offer hope of addressing their needs in the 21st century. The chapter reviews key research and policy documents, drawing on research from the field of neurodevelopmental disabilities and special education needs to set out the context of the study. In this chapter, I also review the literature on adaptive seating and postural management.

To give a sense of identity to the author, the researcher, there is narrative introduction of relevant personal knowledge assembled from 20 years' experience as a paediatric physiotherapist with responsibility for coordinating a regional postural, mobility and seating clinic for children and young people. The complexity of understanding the needs of these children led me to deploy qualitative, interpretive methods, and I include this historical background because professional experience and personal values influenced the development of the research strategy, and how I subsequently interpreted and theorised what was taking place. This section is not a personal reflective account per se. The pieces of the jigsaw, assembled together with accompanying literature, present a brief history of postural management and my role as a paediatric physiotherapist in this field. This summary explains how biomedical models of practice dominated my early career

No published research relating directly to the comfort needs of children with profound and severe learning difficulties using adapted seating and postural management equipment was available. Chapter 3 extrapolates existing knowledge on the topic of comfort and pieces together insights from a variety of sources. This was helpful as it prompted holistic thinking about comfort and discomfort and I was able to examine key issues from a multifaceted perspective. The comfort and discomfort of sedentary workers has received attention in the ergonomic literature, often alongside exploration of definitional terms. Comfort has also been the subject of conceptual analysis in nursing, and if the word discomfort represents a pain descriptor, a growing body of knowledge about expressive pain behaviours in children with severe and complex needs exists. This stage of the research coincided with the gathering of some preliminary data from children and young people who used adapted equipment, but who could use language to express their experiences. Chapter 4 presents this phase.

Chapter 5 maps the development of a methodology for the study. It pieces together a set of representations to convey the requirements for a strategy of inquiry that appears best fitted to the specifics of complex situations. I have included philosophical arguments, which challenge focus on the isolated physical body. The child or young person's presence in the world means as persons they are embodied. In aiming to give some 'voice' to the child or young person, I viewed the epistemological and ontological premises through three lenses: a child and young person lens, an insider practitioner lens and a researcher lens. Of necessity, I have implicated myself in this process. The complexity of understanding these phenomena in situational contexts led me to deploy a naturalistic approach grounded within a post-positivistic philosophical perspective. My past had witnessed the advent of special<sup>2</sup> /adaptive seating and the positive impact this, as a technology, had on the lives of many who, possibly for the first time, were able to leave the confines of institutional life. Remaining a longstanding advocate of the pursuit of better equipment, I have opted for a well established but flexible qualitative research strategy. How I conceptualized case study from these premises I discuss in the final section.

Chapter 6 describes how each of the different methods used for gathering data contributed to the case study approach, and how interviews, participant observation in the classroom or day centre and video recordings complemented each other. The child or young person who needs adaptive equipment, together with the parents,

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<sup>2</sup>A term previously used in the UK to describe seating systems which require special adaptations, modifications or specific individual design

professionals and support workers who, on a daily basis, use observational skills to interpret and ascribe meaning to levels of comfort and discomfort, become integrated units of study and form one bounded case to aid exploration of comfort and discomfort. The study involved thirteen cases. The chapter then describes how I frame the study within the context of ethics; it explains the 'process-principle' deliberations and the regulatory clearance required. Issues of quality are of great concern, especially as I have implicated myself from the very beginning, this becomes the final topic of chapter 6.

Chapter 7 begins with a discussion of the analytical strategy I adopted. Qualitative analysis changes raw data into findings and, in keeping with case study strategy, this entailed a 'within case' then 'across case' analytic sequence. I outline the modes of representation and the sub-processes involved in the management and retrieval of data for each of the separate data sets and follow this with a section explaining how the data were organized and displayed. The next section focuses on the topic of triangulation as I used multiple sources and methods to generate data. Then finally on-going reflexive dialogue reports on the analytical processes used to produce and structure the report of actual findings.

Chapter 8 presents a synopsis of the findings from each case in turn. These contribute to the analytical audit trail and demonstrate the attachment of interpretative meaning to the contextual data. To make this chapter less repetitive, I avoid consecutive extended narrative presentation of all thirteen cases, electing to use data displays for some of the children and young people.

Chapter 9 illustrates interpretation using cross case dialogue as this enables exemplification of analytic similarities and differences between the cases. Here I make use of the themes arising from the analysis to express the essence of comfort and discomfort.

Chapter 10 sees the structured approach to the analysis coming to fruition; here I either substantiate or contrast the accumulative categories with ideas presented in the literature.

In chapters 4, 8, 9 and 10, participants' verbatim quotations are widely used to illustrate and support aspects of the discussion. In order to protect anonymity and confidentiality, I use the pseudonyms as outlined in Table 8.1. For the significant others involved in each case I use the words: parent, teacher, teaching assistant, therapist, and key worker. Each pseudonym also has a case number reference and these locate the



verbatim quotation, video or field extract note extract back to the original source, for example, 1tei1 (case one, teacher interview one); 2ti1 (case two therapist interview 1); 3pi1 (case three parent interview 1). The preliminary phase focus groups I identified with the abbreviation FG 1 and FG 2, and then each group member has a pseudonym. My own involvement in dialogue with participants during the research interviews is indicated by the term 'Int': (an abbreviation for interviewer). Other conventions used in presenting the data include clarification by me of an aspect of a verbatim account is included in square brackets [ ]. A gap in the data presented, denoting a section of an interview that I deemed irrelevant to the context and therefore excluded in the reporting I indicate by the use of a short space in the text ...with three full stops.

Chapter 11 explains how from the outset I implicated myself in the research and that to achieve transparency I had to engage in a reflexive sense with the methodology and analytical processes leading to subsequent conclusions. The chapter begins with some reflections on self. I provide a critical overview of ethics, and then review philosophical and theoretical assumptions underpinning the methodology, followed by a review of the decision-making processes I engaged with during the research process. I then proceed to unite the strategies used for promoting quality in the study. The limitations of the study I discuss throughout this chapter

In chapter 12, the final chapter, I bring together the main conclusions arising from the exploratory investigation. I do not make sweeping statements about the findings but reaffirm the experience of comfort and discomfort belongs to the child or young person, not the parent, not the teacher, and not the therapist. For each research question, I identify what the current project has been able to contribute. Then drawing on the findings I return to the original rationale to pose some questions relating to the project's overall fundamental successes and challenges before bringing the study to general conclusion. I concede there are no encompassing answers. Acknowledging the situated lived experience of the individual within each case enabled balanced interpretations of comfort and discomfort to evolve. Needs of the children and young people, expressed as behaviours, can be shared which warrants on-going focus for all communicative partners. I conclude that some items of equipment can be immensely functional, with the social needs of the children and young people often going beyond therapeutic need. Finally, I offer future directions for practice and research.

In summary, I have provided a broad overview of background information. The following chapter explains why a certain group of children and young people warrant the focus of research to be on their comfort needs.

## CHAPTER 2

### CONTEXT OF EXPLORATION

#### Overview of the chapter

In this chapter, I examine some of the key issues that could influence an experience of equipment use for children and young people with severe physical, learning and communication difficulties. It forms the initial conceptual framework from which exploration commenced. The content reflects focus upon the children, young people and their neurodevelopmental disabilities, the context where they live and learn and the equipment of interest. An examination of current characterization of the children and young people within the United Kingdom (UK) educational system is the starting point. This is followed by a broad overview of issues arising from key research and policy documents, drawing from the field of neurodevelopmental disabilities and special education needs. Then I introduce the topic of adaptive equipment and postural management. At this point, some personal reflections, supported with literature, discern important historical developments. The final section of the chapter considers the topic of joined up working and the importance of services focused around children and families. The following issues permeate throughout and remain fundamental to the development of my conceptual framework; namely the problematic nature of this area of study, the specific health needs and characteristic secondary health conditions possibly contributing to discomfort, and the child or young person's need for extensive support from other people in changing environments.

#### **Children and young people with profound multiple learning difficulties (PMLD) and severe learning difficulties (SLD) who have severe physical disabilities**

Listen to Me is a moving and informative text (Fitton, 1994) by a parent whose daughter Kathy was born with cerebral palsy (CP); she had severe physical disabilities and experienced profound and multiple learning difficulties (PMLD), and was a user of adaptive seating. A short abstract illustrates some personal characteristics:

She could not speak for herself, so she could not say how she felt at different times, how she liked to spend her time, what made her happy and comfortable. She could not explain where her pain and discomfort was. It was not easy to tell from her cries and unhappy sounds whether she was really distressed or bored and annoyed because things were not happening as she wished. She did not understand that some things she did, such as grabbing at interesting objects, pulling at strings or cloths, or pushing things aside could

cause problems and even catastrophes ... We found these [standard equipment] insufficient for Kathy when her spinal problems increased, and she became so uncomfortable that she found it difficult to feed herself and cried to be taken out of her chair and put on the floor. She was fortunate to be referred for a matrix mould. A mould was made out of interconnecting sections, which was exactly adapted to a realistic sitting position, giving her support (p.129).

Everyday functioning is largely determined by an ability to control posture (Carlberg and Bower, 2008), which underpins development of early infant motor milestones, such as, rolling, sitting, crawling and walking. Pope (2007, p 21) states this enables the individual to

conform to the supporting surface, organize balance and stabilize body segments relative to each other and to the supporting surface; adjust to disturbance within the body system itself or an externally imposed one; adopt the most appropriate posture arrangement of body segments for performance of the task in hand; off load the body segments required for movement and secure a fixed point about which the muscles act (p.21).

The postural and movement difficulties of children and young people like Kathy prompt the need for postural management interventions. A detailed description of neurophysiological systems involved in postural control, a highly integrated process under the control of the central nervous system, is beyond the scope of this chapter. The author intends to outline only those aspects relevant to the provision of adaptive seating and positioning equipment; this is because disturbance of the neurodevelopmental mechanisms necessary for postural control may, in the severest of circumstances, prevent a child from holding their head upright or being able to sit without additional support. The body bends and buckles under the pull of gravity (Pope 2007, p.103). These are the children and young people with PMLD and SLD who will require adaptive seating and other items of equipment.

The term PMLD currently signifies the extent of a child or young person's learning difficulties, an educational category corresponding closely with the term 'learning disabilities' as adopted by the Department of Health (DoH) in 1991 for use in United Kingdom (UK) Government publications (Mackenzie and Mc Alister, 2010, p.34). There are international differences in terminology. Intellectual disability is the preferred term in the United States (US). The core feature of intellectual disability [learning difficulty] is significantly sub average general intellectual functioning accompanied by significant limitations in adaptive functioning. This is conceptualised as skills that an individual learns in order to function in the context of his or her everyday life (Shevell, 2009, p.3).

In disorders associated with intellectual impairment, it is usual for other aspects of cognitive function to be impaired as well as the ability to learn.

Children in the UK have special educational needs (SEN), a legal definition within education, if they have a learning difficulty, which means they have a significantly greater difficulty in learning than the majority of children of the same age (Great Britain. Department for Education and Skills [DfES], 2001). A pupil has SLD or PMLD if it is their primary or secondary SEN. Children and young people with PMLD have more than one disability, the most significant of which is a SLD. The group in question have great difficulty communicating (Goldbart and Caton, 2010; DfES, 2001) and may have additional sensory or physical disabilities, complex health needs or mental health difficulties, all of which suggests that this group of children and young people are often very diverse in their abilities (Simmons and Bayliss, 2007; Cartwright and Wincowie, 2005). Not all will have a severe postural and movement disorder, which warrants adaptive seating or physical therapy interventions, for example, some individuals such as those with autism and Down's syndrome have PMLD, but do not require adaptive equipment. Struggling with the lack a singly agreed definition, several authors call for the special needs of this group to be made explicit with regard to service planning, attribution of resources and the provision and equity of service delivery because of their distinctive and complex needs (Bellamy *et al.*, 2010; Crickmore and Dearing, 2007; Gittens and Rose, 2007).

If children or young people with PMLD or SLD require adaptive equipment at school it is documented in their Statement of Special Educational Needs (SSEN) (DfES, 2007), although proposed reforms for implementation by 2014 recommend an 'Education, Health and Care Plan' (Great Britain. Department for Education [DfE], 2011). Currently a SSEN is a culmination of a statutory assessment process, with educational attainments of pupils with PMLD and SLD recorded using the P scale range of the National Curriculum.

The clinical diagnosis of the children and young people with PMLD and SLD varies, but as stated by Shevell (2009, p1)

Neurodevelopmental disability as a concept brings together under one rubric a group of related but clinically distinct chronic disorders whose essential and unifying feature is a documented disturbance in developmental progress either quantitative or qualitative, or both, compared with established norms in one or more developmental domains.

Children and young people with this spectrum of difficulties sometimes have rare neurometabolic or syndromic diagnoses, but for those with an inherent inability to control their own postural position a large number of the children will have the clinical diagnosis of cerebral palsy (CP), a symptom complex featuring heterogeneous aetiology, pathologies, and clinical manifestations. A consensus definition describes CP as, 'a group of developmental disorders of movement and posture, causing activity restrictions or disabilities that are attributed to disturbances occurring in the foetal or infant brain. The motor impairment of CP may be accompanied by a seizure disorder and by impairment of sensation, cognition, communication, and, or behaviour' (Rosenbaum *et al.*, 2007 p.8). Progressive motor disorders, spinal, nerve or muscular diseases fall out of the scope of CP, although the special needs of these children may be similar (Krageloh-Mann and Cans, 2009).

The movement disorder of children and young people with CP is often described in terms of activity and participation using the Gross Motor Classification System (GMFCS) (Rosenbaum *et al.*, 2008; Palisano, 2008), and recently communication difficulties using the Communication Function Classification System (CFCFS) (Cooley-Hidecker *et al.*, 2011). The GMFCS has been widely used for clinical, research and administrative purposes, adopted internationally and used as a stratification system to describe important and significant differences in rates and limits of gross motor development among individuals with CP (Appendix 1). Individuals with total body involvement CP, whose voluntary control of movement is limited and control of posture against gravity difficult, fall into classification level V. In 2005, Ostensjo, Carlberg, and Vollestad found the use of assistive devices and other environmental modifications increase with GMFCS level, in use by 80% of children with GMFCS levels IV and V. More recently, a cross-sectional study found 42% of children with CP used adaptive seating, none of the children with GMFCS level V and only 5% of children with GMFCS level IV could sit in a standard chair (Rodby-Bouguet and Hagglund, 2010).

The GMFCS sits within the framework of the World Health Organization's International Classification of Functioning, Disability and Health (ICF)(WHO, 2001), aiding professionals to make clinical collaborative decisions which take into account the context of needs, wishes, lifestyle and environment of the individual and those concerned with his or her care. The ICF has helped shape perspectives on childhood disability within health care and offers a model of disability and functioning which is holistic and biopsychosocial in orientation (Shevell, 2009, p.6). The framework gives emphasis to the continual bi-directional dynamic interaction between contextual factors and health conditions and allows for 'examination of the dynamic relationship between

the abilities of an individual and the functioning of that individual in different environmental contexts' (Odom *et al.*, 2007, p.9). This is important for children with physical disabilities, SLD and PMLD as they make up a highly heterogeneous population. McDonald, Surtees and Wirz (2004) presented this framework to address the area of adaptive seating for children. Also, teachers supporting pupils with SEN are encouraged to take into account the potential limiting factors of an individual's disability, and Terzia (2005) recommends using the ICF framework to adopt flexible approaches to learning, teaching and assessment in order to maximise learning and participation.

Prior to 1970, children and young people with PMLD did not have a statutory right to educational services. Often separated from their families, living in hospital institutions, those with severe physical disabilities spent most of their lives hidden away lying on mats and beds (Cartwright and Winowie, 2005; Grant *et al.*, 2005; Taylor, 1996; Oswin, 1971). The 1970 Education Act, subsequently strengthened in the past four decades, gave rights to these children. Since 1997, the UK government has placed these and all children at the centre of effort to create a fairer and more just society. Widespread reforms of children's services were set out in the Green Paper 'Excellence for All Children: Meeting Special Educational Needs' (Great Britain, Department of Education and Employment [DfEE], 1997) and developed through subsequent research and legislation. Many disabled children have benefitted from a long term strategy of removing Barriers to Achievement (Great Britain, Department of Education and Skills [DfES], 2004) which reinforces the commitment made in the Green Paper 'Every Child Matters' (ECM) (DfES, 2003) to early intervention, inclusion, the raising of expectations and achievement, and the development of partnership networks.

Many pupils with PMLD still have their learning needs met within special school inclusive environments (Salt Review, 2010), where children with PMLD and severe physical disabilities are educated alongside other children with SLD. Nonetheless, Ashdown and Darlington (2007) report the significant effort that has gone into developing multisensory teaching approaches, sensory learning environments, hydrotherapy and physiotherapy programmes, and physical care routines. Many pupils with PMLD, thought to have no communication ability at all, in the past described as non-communicators, can and do have preferences. They may display early forms of non-verbal communication. This may be pre-intentional, where caregivers who establish relationships with the child decode information, or if the individual shows one or more additional behavioural characteristics such as an alternating gaze between an object and communicating partner, intentional (Bunning, 2009; Sigafos, Butterfield

and Arthur Kelly, 2006; Nind and Hewett, 2001). The classic study by Nind (1996), clearly demonstrates the progress made after the introduction of a teaching approach referred to as intensive interaction. This encourages individuals to learn new behaviours, which encourages others to be with them. Some individuals can learn to make facial regard or eye contact, begin to initiate social contact or develop alternative ways of being with another person. Intensive interaction is one of the strategies described by Golbart and Caton (2010) in a recent publication commissioned by Mencap in partnership with the DoH. It forms part of the 'Valuing People Now' (Great Britain, Department of Health [DoH], 2009) plan to ensure that people with the most complex needs are included and have their needs met.

In respect of on-going health care, interdisciplinary teams endeavour to achieve optimum outcomes for these children and young people; nonetheless, a number of the secondary health conditions often associated with the pathophysiology of the underpinning condition are not always preventable. Respiratory, urinary, and nutritional difficulties are common. It is, however, the atypical development of the musculoskeletal system due to disordered muscle tone, muscle imbalances, atypical limb positioning and difficulties involved in maintaining postures against gravity which contribute to the complexities of postural management and equipment provision. Therapists, who function within a wide social context but with sound knowledge of these common health issues related to musculoskeletal secondary health conditions, are in a key position to ensure that children and young people receive preventative healthcare. For example, in the population of children with CP interventional endeavours, which include orthopaedic surgery, orthoses, pharmacological, and postural management interventions, aim to influence positively the adverse clinical course of children's hips and spines, susceptible to dislocation and scoliosis respectively. Unmanaged, other conditions eventually prevail. Pain, contracture and decubitus ulceration are all conditions known to be prevalent in adult populations living in the pre-1970 institutions (Tsirikos and Spielmann, 2007; Pountney and Green, 2006; Spiegel and Flynn, 2006; Graham, 2002; Hodgkinson *et al.*, 2001, Farmer and James, 2001; Scrutton *et al.*, 2001; Scrutton, 1999; Comstock *et al.*, 1998; Gudjonsdottir and Mercer 1997; Majid Mohammad *et al.*, 1997). Such problems compromise personal care and an obligation to alleviate the distress by minimising the effects is an important element of practice. Addressing postural support in children and young people with severe physical disabilities calls for adaptive equipment.

## **Adaptive seating and postural management**

The word 'adaptive' represents need for customized assessment and provision based on therapeutic principles (Washington, 2002; Roxborough, 1995). Approaches to assessment have been established (Morton, 2007; Pountney *et al.*, 2004), which aid clinical decision making, alongside the identification of potential interventions as part of a family centred approach. Best practice however remains to be standardised (Wright, Casey and Porter-Armstrong, 2010).

Most provision aims to maximize the individual's potential learning and life experiences. For children and young people with PMLD, this may simply be the facilitation of quality one to one time with a teacher or support worker (Golbart and Caton, 2010). Without external support, safety in sitting is of concern for many children and young people with PMLD, and what must not be forgotten is the platform it provides to enable practical access to transportation and variable environments. Minimizing the progression of any soft tissue contractures, all whilst maintaining good tissue viability and physiologic function are other proposed outcomes (Kuckler O'Shea, Carlson and Ramsey, 2006; Mc Donald, Surtees and Wirz, 2004; Ham *et al.*, 1998; Roxborough, 1995; Letts, 1991). In introducing any postural management intervention clinicians are mindful of the barriers to successful implementation, including the need for training and education of those applying the method (Hill and Goldsmith, 2009; Humphreys and Pountney, 2006).

Adaptive seating systems in the 21<sup>st</sup> century perform increasingly complex functions (Tefler, Solomondis and Spence, 2010). It was however the immediate impact on the lives of many individuals four decades ago which led to service developments with adaptive seating, marking a place in the technological developmental history of the wheelchair. A variety of different systems currently exist, and increasingly the clinician is faced with complex decision making and expectation for processes and outcomes to be evidence based, child and family centred. Whilst the words of Watson and Woods (2005) remind us of another line of reasoning, the advent of special / adaptive seating in the 1970's was a response to and catalyst for social change enabling children and adults with multiple and complex needs to leave the confines of institutional life and access the wider community. These authors state

Special/adaptive wheelchair seating developed within the context of diverse environments and social movements. As a concept, it emerged over a relatively short period in different geographical locations, within



different settings and because of disparate socio-political pressures (p.242).

A later focus on positions other than seating arose to address the distorting effects of gravity on body shape. It was however not until the late 1980's that a total approach to the facilitation of correct positions in all postures evolved with studies establishing links between abilities in the positions of lying, sitting and standing (Pountney *et al.*, 2004; Fearn *et al.*, 1992, Pountney *et al.* 1990). The lying position is highly significant in postural management as Hill and Goldsmith (2009, p329) state children are in bed three or four times longer than they are in school. In the past, some individuals sat, but their bodies in neurodevelopment and biomechanical terms were not equipped to cope with sitting. A consensus statement published in 2006 defines postural management as

... a planned approach encompassing all activities and interventions which impact on an individual's posture and function. Programmes are tailored specifically for each child and may include special seating, night-time support, standing supports, active exercise, orthotics, surgical interventions, and individual therapy sessions (Gerricke, 2006, p.224).

## **A historical and reflective perspective**

In this section, I make my involvement in postural management (PM) explicit, as this will have an influence on the developing methodology and subsequent interpretative analysis. Early in my professional career as a community, school paediatric physiotherapist the challenge was to obtain a chair that fitted a child as few children's wheelchairs were available; Nichols (1971, p.232) similarly reported on this dilemma. There was a serious gap in the sequence of sizes suitable for children during their growth and seat inserts, consisting of hand fabricated plywood and black vinyl covered foam inserts, were frequently made for children in need, simply because existing chairs were too large (Holt, Darcus and Brand, 1972). With the increasing number of children surviving previously life-threatening conditions, the mobility requirements of children began to receive recognition, with proposals for wheelchairs tailored to the needs of children. Indoor powered wheelchairs and tricycles for children also became available through the DoH. It was immensely satisfying enabling children to achieve greater mobility and independence, using whatever item of equipment currently deemed appropriate.

Up until then, the sole purpose of wheelchair provision was to increase mobility. Yet, postural problems existed as revealed in the following extract:

Severe spasms will cause the patient to extend the hips, and thus span the wheelchair, arching from the top of the backrests to the footrests or floor. The patient will tend to slip off the chair or so alter his position that he is no longer reasonably comfortable, and he may not be able to regain his usual sitting posture (Nichols, 1971, p.230)

An essentially orthopaedic perspective influenced many of the clinical decisions made at this point in my career causing me to view problems as largely biomechanical. Limbs were supported with calipers. At this time, adults with the severest of all disabilities were cared for in institutions (Warnock, 1978); children still attended hospital schools, and the secondary complications and long-term consequences coupled with children surviving into adulthood remained unexplored. Perhaps naively, or because the outcome of achieving mobility in a previously immobile child was so obvious and successful, there appeared to be little reason at that stage of my career to question practice. That was until children with PMLD started attending local authority schools for children with special needs. With this came my entry into the field of special/adaptive seating; a journey had begun.

Overwhelmed at times by the complexities of need, an overarching aim of enabling each child to achieve his/her potential became the concern for many paediatric physiotherapists working in the field. Knowledge about the benefits of postural positioning led therapists to reason that neuromuscular and physiological responses might be influenced by the use of external devices, which in turn could promote a child's functioning (Falk-Bergen and Colangelo, 1985). This prompted many therapists including myself to look towards assistive technology as a means of achieving those aims, whilst embedding knowledge and understanding of human movement into the process. Unfortunately, in the UK, the only wheelchairs available for children who could not sit were the Cell Barnes, the Amesbury Avon and the Amesbury Bantam range of chairs. The Cell Barnes chair had an angled backrest and the Amesbury Avon chair could tilt but were neither supportive nor contoured to body shape. The Amesbury Bantam chair was simply a conventional style wheelchair with firm cushioning. Without additional pillows for support, the children slumped, collapsed, or slid forward and the chairs were extremely difficult for carers to manoeuvre. Consequently, children and young people were spending time out on beanbags.

Nonetheless, the late 1970's saw a surge in new ideas and developments directed towards addressing the needs of individuals with complex postural difficulties, across different parts of the world (Ring, 1978). Among the many changes was the manufacture of individual contoured seats (Strange, Harris and Nichols, 1978). My own

emerging interest in the field of postural management was enhanced through the nomination of two 'posturally difficult to manage' children from my case load being elected to take part in a pilot clinical trial (Biological Engineering Society, 1978). This involved the manufacture of customized body moulds that would insert into a wheelchair, the overall aim of provision being postural support. A feature that was not available in commercially available devices at the time. The trial was successful, and led to my subsequent involvement in the establishment of a regional children's interdisciplinary wheelchair clinic. Similar and different approaches existed in different parts of the UK, the subspecialty of specialized seating and mobility was beginning to develop. The interdisciplinary regional children's wheelchair clinic, subsequently renamed to include seating in its title, became a forum for problem solving difficult postural, seating and mobility problems (Jarvis, 1985), albeit equipment and funding was still limited, and in truth many solutions were developed intuitively. Similar developments have been documented (Biological Engineering Society, 1979).

As the clinic had a regional remit, I watched many children become adults, observed the natural history of the underpinning disorder on the developing child, and the response to interventions of the time. Words spoken by Scrutton (2004 p.6) ring true:

...for time is not on the side of the child: childhood is limited by growth and cannot be extended arbitrarily for therapeutic convenience

In the early years, clinical referrals likely surpassed opportunity to build up systematic collective evidence of effectiveness, outcome measures were observational and subjective. Experiential accumulation of knowledge was similar to that reported by Pope (1996, p.156)

compromise was almost inevitable and goals of provision needed to be prioritized as assessment, provision, and usage of equipment was complex and context dependent.

### **Contemporary adaptive seating and postural management practice**

An ever-increasing variety of equipment has become available with the body of literature relating to this topic expanding. Presumptions made about comfort and discomfort will be forthcoming in chapter 3, as these key words rarely featured within the abstract of journal articles. In this section, contemporary adaptive seating and postural management practice was the focus of a literature synthesis, extracted from the following databases: CINAHL, PubMed, ERIC, Medline, Cochrane, ProQuest Nursing and Allied Health Source, ASSIA, Zetoc, Applied Social Sciences Index and Abstracts, Science Direct Freedom Collection and Web of Knowledge, accessed using

NORA search engine. UK paediatric therapy journals were also hand searched for relevant articles.

The parameters of the search were broad, not exclusive to CP, but encompassed children or young people with neurodevelopment disabilities, including CP, multiple disabilities or PMLD up to 22 years of age. The following additional key words/terms were used: adapted seating, special seating, specialized seating, postural management, 24-hour postural management, night time positioning, postural care, postural support, standing devices, sitting, standing or lying orthoses. The search revealed quasi experimental group designs, single subject design, descriptive accounts, case studies and surveys. One noticeable feature of the search was the number of literature reviews and evidence reviews on the topic, the more current updating critical synthesis of earlier reviewed literature (Bush *et al.*, 2010; Glickmann, Geigle and Paleg, 2010; Wynn and Whickham; Gough, 2009; Chung *et al.*, 2008; Keeth *et al.*, 2008; McNamara and Casey, 2007; Michael, Porter and Pountney 2007; Stavness, 2006; Farley *et al.*, 2003; Roxborough, 1995). A data extraction table (Appendix 2) summarises information on the purpose, search strategy, findings and recommendations from each review. Empirical studies of original articles dating from the 1980's included in the reviews were in the main focused on the sitting postures achieved through use of adaptive seating and consequential change on aspects of functioning, or postural management care plans, which include other items of positioning equipment. A number of these reviews make use of quality assessment scales, with levels of evidence scored according to classification schemes.

Since the early review of the efficacy and effectiveness of adaptive seating by Roxborough (1995), a number of reviews have narrowed their focus. McNamara *et al.* (2007), Stavness (2006), and Michael, Porter and Pountney (2007) give focus to seat design features. Stavness reviewed the effect of positioning on upper extremity function, with all the included studies addressing alignment of the pelvis. The effects of seat inclinations on postural control, muscle activity and functional use of the upper limb was a feature of the review by McNamara *et al.* (2007), and tilt of the overall seat was the topic of the review by Michael, Porter and Pountney (2007). Some positive outcomes emerge from the review findings, although concluding statements about the imprecision of included studies remain a prominent feature. Ryan (2012), summarising reviews published between 1995 and 2010 that systematically searched for the effectiveness of adaptive seating interventions in children with CP on postural control and management, identifies the positive outcomes as improved postural stability, trunk extension, upper limb functioning and cognition. The review by Michael *et al.* (2007)

which found some evidence for the benefits of posterior tilt in reducing interface pressure under the pelvis was however not included in Ryan's review as 9 of the 19 studies included adults with spinal cord injury.

A small number of recent reviews have considered other types of adaptive equipment. Glickmann, Geigle and Paleg (2010) and Bush *et al.* (2010) reviewed supported standing equipment for children and adults with neuromuscular disorders and cerebral palsy respectively, and Wynn and Whickham (2009) night time positioning equipment. Glickmann, Geigle and Paleg (2010), in scoring studies according to an evidence classification scheme found moderately strong data to support bone mineral density increase; weaker data in support of tonal change and subsequent range of movement increase, but inconclusive data for other benefits of using supported standing. Data examined by Wynn and Whickham (2009) suggest that night-time positioning reduces the rates of hip subluxation, improves care, reduces pain, and that upright sitting, compared with lying, improves breathing. Other reviews extend their focus, taking into account all items of equipment included in the care plan (Appendix 2). Farley *et al.* (2003) for example concluded stronger evidence for physiological level outcomes than functional outcomes, but unlike several of the adapted seating reviews did not restrict their reviewed published studies to children with CP. Those studies, which do restrict the target population to children with CP show increasing use of the validated classification system, the GMFCS, widely used in CP research. This framework being a more recent recommendation by reviewers, due to the inherent difficulty they experienced in making cross study comparisons (Chung *et al.*, 2008; Ryan, 2012). Chung *et al.* (2008) was the only review to focus exclusively on adaptive seating outcomes for non-ambulatory children with CP, and of the fourteen studies included, only one study identified the children in the study with PMLD.

For non-ambulatory children, the provision of adapted seating equipment also includes wheeled mobility. This, in particular, has the potential to enable greater participation in life situations for children, young people and their families, and mobile adaptive seating in the classroom supports the concept of inclusion. In 2004, Mc Donald, Surtees and Wirz proposed use of the theoretical ICF model for adaptive seating evaluations, as this encourages professionals to take a holistic view of the individual, his or her family and other caregivers and the varying environments of use. This model fits with practice. Yet the systematic review by Chung *et al.* (2008) found the outcome of interest in all the reviewed studies still focused primarily on the body structure and function components of the ICF model, with very little focussed attention on enhanced

participation in the social skills of daily life as a consequence of PM. The same year, a systematic review of the impact of general assistive devices on the components of functioning defined by the WHO ICF (Henderson, Skelton and Rosenbaum, 2008) reported positive outcomes. However, these were mainly child focused, with little attention paid to caregiver focused outcomes. One perceptible feature of the current literature review search was the emergence of studies beginning to address contextual factors (Appendix 2). Hutton and Coxon (2011) gathered qualitative data from a purposive sample of staff in four primary schools, whilst Maher *et al* (2010) used a survey to explore factors influencing postural management in the special school setting. Tefler, Solomonidis, and Spence (2010) and McDonald, Surtees and Wirz (2007) surveyed the views of parents and school staff, and parents and therapists respectively, whilst Ryan *et al.* (2009) examined the impact of adapted seating on the everyday functioning of families (Appendix 2).

### **Collaborative working**

Children and young people with disabilities require the combined effort of parents, teachers, therapists and other multi-agency team members to help them overcome a number of difficulties at home and school. As the field of biomedicine expanded so has empirical work with families. Such research aids understanding of family coping and adjustment. In addition, research approaches are increasingly giving recognition to the positive effects the birth of a child with disabilities can have on families (Blacher and Hatton, 2007, p.536). In contrast, there are reports, some from the turn of the 21<sup>st</sup> century, which suggest professionals are not supporting families. Carpenter (2000) reports criticism of both professionals and services about lack of continuity and coordination, insensitive and ill-timed approaches, which fail to enhance parenting confidence.

In consequence, the concept of joint working now underpins UK policy documents, green and white papers (DfE, 2011; DfES, 2003; Sloper, 2004; DoH, 2001). The government aspires to transform services for all disabled children to make this happen. Irrespective of their very complex health and learning support needs, they, as with all children, are part of a family unit. Thinking about disability in non-judgemental ways helps service providers understand the generic elements of parenting when a family is raising a child with complex needs, which should urge professionals to find ways to move across boundaries between health, education and social care (Rosenbaum, 2004, p.22). There are suggestions that this is working (Boddy, Potts Statham, 2006; Abbott, Watson and Townsley, 2005).

Through the Aiming High for Disabled Children programme (DfES, 2008), the UK government has made disabled children a national priority. It wants all families with disabled children to have the support they need to live ordinary family lives, as a matter of course (DfES, 2007). There is commitment from the Department for Children, Schools and Families (DCSF) and the DoH to improve the services and support available to disabled children and their families. The Government's transformation programme supports the aims of ECM and the Children's National Service Framework and places particular emphasis on the importance of joined up working and services focused around children and their families. Community equipment and wheelchairs was one of the services highlighted for reform as it plays a very important part of many disabled children's lives (NHS Confederation, 2009). Everyday demands may be tiring, but psychosocial approaches to working with families who have a disabled child have challenged the notion that everyday family living is burdensome. Current UK government policies and legislation are challenging professionals to be child and family centred.

## **Conclusion**

In this chapter, I have reviewed the literature to provide an overview of the children and young people who use adaptive seating and other items of positioning equipment as part of everyday living. The term PMLD currently encompasses those children and young people with the severest of learning and communication difficulties, some whom also have a physical disability requiring postural support across lifespan. Since the 1970's the beneficial and life changing effects of adaptive seating as an environmental resource have been recognised (DoH, 2010). Adaptive seating has the potential to enhance social and environmental participation for all children and young people, allowing access to schools, leisure and other services. Many factors influence the clinical decisions made by practitioners when they assess a child and young person with disabilities for adaptive equipment. The influence of positioning on functional outcomes is one feature often addressed in evaluative studies, but empirical evidence remains inconclusive. Importantly, the dynamic interaction between contextual factors, adaptive equipment and those with neurodevelopmental disabilities is beginning to receive recognition in the literature. The experience of those with communicative capacity to speak out about their need for comfort, knowledge of comfort across other discipline areas and known causes of postural and equipment discomfort will be explored in the following chapter as a possible means of enhancing understanding about the experience of those without communicative capacity.

## **CHAPTER 3**

### **MOVING FORWARD TOWARD EXPLORATION OF COMFORT AND DISCOMFORT**

#### **Overview of the chapter**

Literature on the topic of comfort and discomfort is central to this chapter. An early search focused on the physicality of these two concepts. Comfort is often an assumed premise and rarely examined in isolation from other outcome domains within the context of adaptive equipment for children and young people with PMLD and SLD. Although parents and others report on comfort states in studies evaluating the efficacy of adaptive equipment. Practice-based experiential understandings led me to believe that individuals, if given the opportunity, will express their likes and dislikes about equipment, which is critical to their everyday functioning. I therefore reviewed the relevant literature focused on those with communicative capacity. Comfort I found was a subjective outcome in the evaluation of wheelchairs for adults, workplace seating and other items of functional equipment, but children's views were not in abundance. Knowledge of this type could have value in furthering exploration of the topic in children and young people who lack the capacity to use language. Therefore, at the outset of the current study a preliminary data-gathering phase took place with those who could (Chapter 4). I did however find on-going reference to the nature of the two dimensions across discipline areas, which cultivated my thinking and developing methodology for this study. In nursing for example, holistic comfort has been the subject of conceptual analysis and publication of a mid-range theory of comfort. Discomfort is often considered a pain experience, albeit of a milder nature, but if there is affinity to pain, where does this leave distress? It emerged that my own early physical representation of these concepts was narrow.

The sections of this chapter together create a multidimensional perspective of comfort across discipline areas, providing initial interpretation of substantive issues perceived to have applicability to subsequent understanding of the experiences of children and young people using adaptive equipment. First, I examine studies that have explored the experiences of people with severe neurodisabilities who use a wheelchair but who have the capacity to communicate their views using language. Then I examine literature that refers to the comfort of children and young people using adaptive equipment. I follow this with a section, which provides an overview of potential sources of discomfort for adaptive equipment users. As adaptive equipment applies



biomechanical principles to the human body, I then explore issues of comfort and discomfort in the field of ergonomics and then the field of nursing. Finally, I provide an overview of current research into distress and pain as experienced by people with learning disabilities. The conclusion draws together some of the emerging issues as data collection continued.

### **People with neurodisabilities who can express their views about wheelchair seated comfort**

Prior to the latter part of the last century wheelchair seating comfort was not a cause for concern. Clinicians considered ways to address causative discomfort factors (Harms, 1990), but user evaluations or perspectives were rare. Attention focused on the technology (Hobson and Crane, 2001) and ways to prevent pressure ulcers. Yet the importance of comfort was recognized; for example, in his memoirs, Jehan Lhermite, the Flemish Nobleman who designed the first known invalid chair for king Phillip 11 of Spain wrote '[it] was worth ten times its weight in gold for his majesty's comfort' (Tudor-Craig, 1998). By the late 1990's, comfort as an unmet need was being recognized in survey investigations of assistive technologies. Those with the capacity to communicate were expressing their views and experiences, whilst other researchers began to address comfort using objective measures.

Weiss *et al.* (1999) used the Quebec User Evaluation of Satisfaction with Assistive Technology (QUEST) to evaluate satisfaction with wheelchair seating aids. This is a client centred questionnaire and outcome measures contain 12 questions, eight about the characteristics of the device under evaluation and four about service provision. In this questionnaire, one question related to comfort. The clients in this study had various diagnoses but the variable comfort was identified as the most important consumer criterion. Yet this evaluated as the least satisfying. More recently, Bergstrom and Samuelsson (2006) used the QUEST to evaluate manual wheelchair satisfaction in 205 adults with spinal cord injury. Due to the generic nature of the QUEST, the researchers included seven more focused questions about the seating device. The findings reveal a high level of satisfaction with certain wheelchair properties, for example, propulsion, but a discrepancy between users with regard to comfort in sitting during various activities. This finding prompts discussion. Wheelchair users need to perform functional tasks from a sitting position and comfort is important. A large percentage of wheelchair users with spinal cord injury will have disturbed sensation and will not experience the buttock discomfort, but may experience discomfort in other areas. Trail *et al.* (2001) also used a survey to ascertain the views of 42 patients with amyotrophic lateral sclerosis. More of the users in this study needed caregiver assistance for activities of daily living and

spent an average of 5 hours (range 0.5 -16 hours a day) in their wheelchair. This survey included a satisfaction with comfort question, with 59.5% of the sample reporting aches and pains.

In 1999, Monette, Weiss-Lambrou and Dansereau investigated factors influencing discomfort more closely using focus group methodology and nominal group technique. Six experienced wheelchair users and three occupational therapists participated in this study and identified the following sources of discomfort: 'having pain, feeling the need to move, feeling unstable, feeling physically tired, feeling a burning sensation and sliding out of the wheelchair'. Monette *et al.* (1999), also considered comfort and described this as feeling good, feeling supported in the right place, feeling little pressure under the buttocks, feeling stable and feeling satisfied. This study raised the possibility of multidimensional influences on comfort. In 2001, a consensus forum on wheelchair seating identified the comfort of wheelchair seating as one of the core areas in terms of future research (Geyer *et al.*, 2003). The expert panel producing the following definition of wheelchair seating discomfort.

A negative feeling, reaction, or sensation that usually occurs over time, can often limit a person's ability to function in their mobility system, and therefore may adversely affect their expected or desired role within society. It often first presents itself as an unconscious desire to change body posture. It is often associated with one or more factors such as instability, forward sliding, excessive heat build-up, stiffness, excessive localized soreness or pain, spasticity, or stretch. It may be specific in location or generalized, but diminishes when the person is able to initiate frequent changes of the seated posture or is no longer in the mobility device. It can be a precursor to the development of secondary conditions (Geyer *et al.*, 2003, p.122).

In consequence, on going research furthered the development of a more specific seating discomfort assessment tool for wheelchair users with near normal sensation (WcS-DAT) (Crane *et al.*, 2007; Crane *et al.*, 2005; Crane *et al.*, 2004). With a focus on seven body areas at risk of discomfort, the comprehensive questionnaire included five items related to comfort and eight related to discomfort. A 7-point Likert scale was used to score the items. A further study established the test-retest reliability, internal item consistency and concurrent validity of the tool. These findings support its use as a reliable and valid tool (Crane *et al.*, 2005). Whilst this is a promising evaluative tool for both the users and service providers, it does infer that the person will be able to use self-report scales. This is not possible in children with multiple and complex needs. Nonetheless, these studies aid understanding of the reality of a discomfort experience being present amongst a group of individuals who potentially have similar or greater limitation of movement opportunities available to them. They, likewise, have secondary

spinal and pelvic deformities related to a neurological condition and may not be able to change their postural position independently.

As client-centred methodologies are gaining acceptance more studies report user perspectives. Dewy, Rice-Oxley and Dean (2004), using a phenomenological approach, interviewed 23 fulltime wheelchair users with multiple sclerosis who spent between six and 14 hours each day in their wheelchair. The aim of the study was to compare the experiences of tilt-in-space wheelchair use and conventional use. Comfort was one of the themes, which emerged from the data collected. In the words of one participant in the study, it is 'The Rolls Royce of wheelchairs', this one [old one] is a Ford Cortina'. Other clients reported, 'this chair is a mobile armchair', or 'my bum is so sore'. Surprisingly, none of these studies set out to investigate comfort or discomfort factors. Secondary analysis would be necessary to reduce the data into additional categories. The respondents in all the above studies had the communicative capacity to speak out about any discomfort experienced; children and young people with PMLD may have equal risk because of similar body function disturbances.

### **Comfort of children and young people using adaptive equipment**

Seating systems emerged to meet a need in the 1970's and by the early 1980's the most frequently prescribed supportive seating system was the moulded seat (Nelham *et al.*, 1988). During this era, comfort was not a neglected topic. The early proclaimed benefits of moulded seating being 'functional position, comfort, pressure distribution and the possibility of holding a deformity' (Ring, 1979 p, 67). Johnson and Rodger (1979) reported on a comparative crossover study of twelve participants designed to evaluate the benefits of three types of moulded body support. A questionnaire was answered by the participant or if this was not possible the caregiver, this included a question on comfort. Statistical analysis was not possible due to low numbers, but a system of scoring gave meaningful comparisons of the benefits of different supports. Client satisfaction with comfort in these early studies was a team effort with representation from therapists, carers or parents (Fisher and Seeger, 1987). Green and Nelham (1991 p.203) also spoke of comfort and its importance, particularly for children where the primary consideration of adaptive equipment provision was not 'the application of biomechanical principles to achieve significant improvements' but to 'apply the principles of postural stabilization' so that maximum function and comfort could be achieved.

As the scope of provision emerged to encompass an evidence outcome orientation (Smith, 1996), comfort appears as an assumed premise in a number of the evaluative studies. Roxborough (1995), reviewing published research evidence for the effectiveness of adaptive seating outcomes, concluded that seating comfort was one of the hypothesized outcomes not researched. These comments were replicated by McDonald Surtees and Wirz (2004) almost a decade later. Reporting on the growing demand for an alternative to supportive wheelchair seating, Pain, Pascoe and McLellan (1996) likewise drew attention to the topic of comfort in a DoH sponsored evaluation into multi-adjustable upholstered chairs for children with disabilities. The purpose of the study was to compare the effectiveness of support features and the comfort of the upholstered chairs. This study reports that, when the children were unable to give verbal feedback about their comfort, the therapist heeded non-verbal indicators of discomfort. Poor response rate to the postal survey raised concern, but from those responding the chairs were reported as comfortable by a large majority.

Neilson *et al.* (2001) describe a preliminary investigation to evaluate carer satisfaction with seating interventions for people with PMLD. One of the tools utilized was a questionnaire, with the question themes based upon carers' personally reported objectives prior to the intervention. These included sitting comfort, posture and function. The overall results demonstrated physical, functional and quality of life benefits for the client and carer satisfaction with the results. Due to the contradictory findings, these authors raised questions about the value judgments made by clinicians and carers. Conflicting results were also reported in a study by McDonald, Surtees and Wirz (2004). These researchers developed a questionnaire for both parents and therapists of fifty-nine children with multiple and complex needs to investigate opinions about the child's individual seating system. In the study, one question asked for a rating of the child's comfort, another asked about discomfort. The findings reveal parents were confident that they knew when their child was comfortable and were accordingly consistent with their responses. Therapists, however, were least consistent when answering the questions related to comfort such as 'the child is always comfortable in their seating system'. These authors concluded that the differences might relate to the amount of time spent with the child, or parents' confidence in communicating with their children. In 2007, McDonald, Surtees and Wirz further categorized the results of this questionnaire into the domains of the ICF and identified that therapists considered body functions and structures to be responsible for comfort, followed by environmental and personal factors. This was in contrast to the parents who perceived environmental and personal factors to have more effect on their child's comfort (p323). These

researchers further categorized the reverse question, both parents and therapists agreed it was the child's body structure which caused the most perceived discomfort.

Some children who use adaptive equipment use language to communicate and, on occasion, their voices do appear in the literature. In 1996, children with physical disabilities helped design a new adaptive paediatric seating system and during the trial evaluated postural belting, cushion firmness and upholstery texture using a three faces rating scale. A greater percentage of the children using wheelchairs in this study preferred softer cushions, and the reason stated 'it was softer and more comfortable' (Rigby *et al.*, 1996, pp.74). Children evaluated standing frames in a study carried out as part of the Medicines and Healthcare Products Regulatory Agency (Daniels, 2005). Six of the seven children in this study actually liked their own frame because it was comfortable; however, in eleven of the fifteen trials, the trial frame was preferred above their own because it was more comfortable. For children, these findings suggest comfort has meaning.

## **Potential sources of physical discomfort**

### ***Unstable postures***

Adaptive equipment discomfort may be due to a number of interrelated factors. Firstly, the human body is an incredibly complex biological system subject to fundamental laws of mechanics. Therefore, children and young people with severe postural difficulties who have little antigravity control may experience discomfort from high or prolonged loads placed on body structures. Pope (2007, p.1) describes how a person's ability to organize posture and move about develops 'within the environmental constraints of gravitational forces'. Even the lying posture adopted during sleep is still prone to this gravitational force although generally fewer demands occur in this position (Goldsmith and Goldsmith, 2007). The use of technology to compensate for a lack of intrinsic postural stability creates additional mechanical forces on the musculoskeletal body, usually in an effort to achieve a stable bodily position. During waking hours of the day, frequent use of the sitting posture is likely. However, this is an intensely unstable posture (Corlett, 2008; Cranz, 2000; Cranz, 1999), and during the 20th century identified as a major cause of back pain and discomfort in the seated workplace. Extensive research in this field of study led to greater understanding of the biomechanics of sitting. Aspects of this knowledge base influenced the design of equipment for people with disabilities.

De Looze, Kuijt-Evers and van Dieen (2003) explain how the sitting position, the seat and the task expose a person to loading factors. The cascade of resultant responses may be mechanical, biochemical or physiological, all with the potential to cause discomfort. Key understandings draw from ergonomic research including evaluative studies of spinal loading. These electromyography and disc–pressure studies reaffirm the detrimental effect of inadequate postural control, which can cause localized, short term discomfort due high levels of stress building up in the tissues, mostly in the ligaments under tension and within the intervertebral discs and other tissues under pressure (Eklund, 2008; Corlett, 2007; Harrison *et al.*, 1999; Corlett, 1989). , Ergonomically designed seats, long considered an important consideration in preventing damaging health problems in sedentary workers, do not fully address the problem. Users' sitting preferences, a choice to choose free postures, the need to offer comfort and postural support without compromising freedom of movement, and the avoidance of constrained, awkward or prolonged postures are increasingly recognized as important considerations (Eklund, 2008; Leuder and Noro, 1994). Risks to health continue to exist when there is no possibility of relief or postural change, and Corlett (2006) further argues that the human consequences of the interaction between the seat and the workplace must be addressed in a holistic way. In consequence, participatory ergonomics is developing as a discipline (Wilson, Haynes and Morris, 2005).

Similar to the seated worker, persons with diminished postural control, with the passage of time, might experience discomfort and diminished functional ability (Pope, 2007, Green and Nelham, 1991; Zacharkow, 1988). Yet the children and young people who use adaptive seating do not have the same movement opportunities. If the design does not fulfil expectations or is ill fitting, and the child or young person is inappropriately positioned, possibly for prolonged periods, with the situational context amiss, they may be unable to compensate for the inadequacies.

Alongside the developing understandings, a number of studies, whilst not specifically investigating postural management discomfort, identify the possibility that discomfort might be occurring in the study population of interest. First, come reports from individuals who possess the verbal capacity to express discomforts. Engel *et al.* (2002), and Schwartz *et al.* (1999), report the high incidence of pain in individuals with CP, with the location of pain similar to the general population of people with sedentary lifestyles. Musculoskeletal sources of pain arise from secondary health conditions that can be common and severe in children and young people with severe physical disabilities, and management often involves surgical procedures (Ward and Kadies, 2002; Hodgkinson *et al.*, 2001; Owers *et al.*, 2001; Stasikelis, Lee and Sullivan, 1999). Severe scoliosis,

for example, is common in children with CP (Saioto *et al.*, 1998), particularly those with GMFC level V and surgical procedures are often justified with regard to making improvements in sitting equilibrium, pulmonary function and comfort. A perception that the child appears more comfortable after spinal fusion in these studies is suggestive of pre-operative discomfort. Implicated in the development of scoliosis and pelvic obliquity is the unstable painful hip, which greatly affects sitting posture (Graham, 2002, Hodgkinson *et al.*, 2001; Scrutton *et al.*, 2001; Scrutton, 1999; Comstock *et al.*, 1998; Gudjonsdottir and Mercer 1997; Majid Mohammad *et al.*, 1997).

A longstanding, desirable outcome of orthopaedic and therapeutic intervention is the desire to decrease development of biomechanical mal-alignments that lead to muscle and joint contracture and bony deformity often caused by imbalance of muscle tone in children at high risk (Falk-Bergen and Colangelo, 1985; Nichols, 1971 p.22, Fulford and Brown, 1976). Furthermore, a classic paper by Tardieu (1988) states that muscles require stretch for at least six hours to prevent tissue adaptation, a finding which gave focus to current postural management programmes. Small studies show promise (Pountney, *et al.*, 2009; Hankinson and Morton, 2002; Pountney, 2002), but evidence is still limited (Lloyd, *et al.*, 2011; Pountney and Green, 2006). These few reports are in contrast to some of the many reports documenting the period-spent sitting in a wheelchair. This leaves these small-scale studies, which have attempted to evaluate postural management programmes (PM), open to critical review. Gough (2009) raises an interesting argument. He postulates that changes occur within the morphology and intrinsic material properties of the musculotendinous unit of muscles, particularly in those children at high risk of developing deformities and that by pursuing a PM programme an element of stretch may therefore be a factor contributing to discomfort. Another factor to consider is duration of equipment use if stretch causes discomfort.

### ***Prolonged interface pressures***

Interface pressure due to the length of time spent seated in an item of PM equipment is another factor to consider. Pressure, particularly over a bony prominence due to mechanical loading, leads to the physiological response of hypoperfusion in compressed tissue; the compromise of blood flow eventually producing a discomfort sensation (Baldwin, 2001). Positional change is the natural response to this intrusive bodily sensation of discomfort, experienced if an individual adopts a sitting position for too long a period, even for people without mobility difficulties. Consequently, the sitter spontaneously moves or fidgets to decrease this discomfort. In vulnerable at risk, populations the detrimental consequence of these physiological responses may result

in tissue breakdown if high-pressure concentrations go unrelieved (Haalboom, 2005; Anthony *et al.*, 1998). Research identifies many risk factors associated with the formation of pressure ulcers, including sitting posture and lack of spontaneous body movement. A poor sitting posture can significantly affect pelvic orientation and ischial pressure (Koo, Mak and Lee, 1996). It is however the duration of high pressure concentrations and the anoxia sustained that determine the degree of ischemia.

The high costs associated with pressure ulcers have led to on-going technological research into occupant-surface interface pressures and the use of pressure measurement systems to evaluate the relative performance of different pressure reduction systems. However, the vast amount of work linked to tissue viability has focused on the adult population. For children, the literature on prevalence and incidence of pressure sores is sparse (Kottner, Wilbourn and Dassen, 2010), more so for those occurring in the community, although school nurses, and the parent of a child with PMLD have noted the occurrence (Sim and McDonald, 2003; Jones, 1997; Fitton 1994). Lack of spontaneous body movement has long been linked to a high incidence of pressure sores (Exton-Smith and Sherwin, 1961), and one of many risk factors which exist in this group of children and young people. Improved awareness and provision of pressure relieving interfaces within seating systems minimise the risk, but how effective are they at addressing comfort?

### ***Duration of postural position***

With reference to the biomechanical loading and physiological responses described above, the length of time spent seated in an adaptive system or positioned in another item of PM equipment is a further factor to consider. In sedentary workers, sitting discomfort increases over time, with relief coming from postural movement (Kyung and Nussbaum, 2007; Pynt, Higgs and Martin 2001; Helander and Zhang, 1997; Leuder and Noro, 1994). The total frequency of postural changing appears to be a sensitive indicator of postural distress and discomfort. The relationship between time and mechanical loading, both in terms of tissue viability and discomfort, becomes real when one considers there are reports of users of wheelchair seating aids spending 11 hours or more each day in their wheelchair seating device (Goldsmith and Goldsmith, 2007; Weiss-Lambrou *et al*, 1999). There is a lack of published work directly related to time intervals for re-positioning; however, in ergonomic field studies of seating, subjective comfort ratings have been found to decrease with time, whilst the frequencies of in-chair movements increase significantly (Fenety, Putnam and Walker, 2000; Fernandez and Poonawala, 1998).



## **The multidimensional nature of comfort and discomfort**

### ***In the field of ergonomics***

On-going empirical research and development in the manufacturing and design industry has led to considerable debate about the two topics, 'comfort' and 'discomfort'. Much of the work relates to individuals seated in the workplace where optimal human performance in the environment becomes important. In 1958, Hertzberg (Zacharkow, 1988, p.10) suggested a realistic approach to use in the assessment of chair comfort was to regard comfort as the absence of discomfort. A seat, he argued, cannot provide comfort but discomfort can be eliminated. Branton (1966, p.10) accepted this view and in his investigation into the comfort of easy chairs focused on gradients of discomfort. He stated 'we do not sit in a chair to enjoy the seat, but to enjoy ourselves'. The absence of discomfort denotes a state of no awareness at all of a feeling and does not necessarily entail a positive effect. Much later, Pheasant (1991, p.212) referred to this as 'a state of mind which arises in the absence of intrusive bodily sensations'. Accordingly, Shen and Parson (1997) described discomfort as being a generic and subjective sensation that arises when physiological homeostasis, psychological wellbeing or both are negatively affected.

In the field of ergonomics, clarity of definition became important as tools were required to compare the design features of chairs, comfort being a feature worthy of investigation. A classic study by Shackel *et al.* (1969) in Helander (2003) validated the General Comfort questionnaire for measurement of chair comfort, based on subjective rating scales. Helander (2003) summarizes a number of studies dating from the 1960's to the 1990's which used this questionnaire, including his own (Helander *et al.*, 1987); all struggled to obtain any significant differences between the seats, in spite of chair feature and body area checklists employed as additional measurement tools. Helander (2003), quoting the renowned findings of Akerblom (1948), concluded that ergonomic design features of chairs are indistinguishable because there are no nerve endings in the intervertebral discs, and therefore the higher disc pressures as a consequence of sitting cannot be perceived.

Disillusionment with comfort ratings, therefore, led to exploration of its multidimensional properties, with conclusions suggesting comfort is a concept in its own right, not just the lack of discomfort. In field study trials, Zhang *et al.* (1996), Helander and Zhang (1997) identified different factors influencing these two constructs. For chair comfort, these were feelings of 'well-being', relaxation, relief and aesthetic impression, whilst the

factors influencing discomfort related to biomechanics and fatigue, due to the passage of time accumulated during the working day. The outcome was a chair evaluation checklist, which can be used to measure comfort and discomfort independently. Therefore, as the chair itself does not transmit a positive sensation of comfort the rate of onset of discomfort depends on seat characteristics, and as suggested by (Pheasant and Haslegrave, 2006) user characteristics and task. However, as defined from the perception of the individual, if fatigue is due to the passage of time accumulated during the working day the two constructs can sometimes support and sometimes counteract the use of ergonomically and biomechanically sound seating (Eklund, 2008). Biomechanics and fatigue would therefore appear to be important in consideration of adaptive seating discomfort.

For designers, the outcome of the chair evaluation checklist was a step forward. Nonetheless, such progress infers that the person will be able to verbalize their discomfort, or dissatisfaction with a seat design, and vary his or her posture following the onset of discomfort. Unfortunately, the child or young person with physical, learning and communication difficulties is reliant on others to enhance variation of movement and interpret discomfort cues.

An exploration of comfort and discomfort in the field of ergonomics has reinforced the complexity of this topic area. A number of factors were found to influence the two constructs. Therefore, possibility exists that similar factors contribute to the experiences of those children and young people who use adaptive equipment. The importance of undertaking a study in the natural setting is substantiated by these findings.

### ***Comfort as a dynamic process***

The discipline of nursing has explored a number of interpretations of the construct comfort, including comfort discomfort continuums. In earlier works, the exact nature of comfort evaded identification; definitions were diverse and often drawn from different perspectives. Siefert (2002) and Tutton and Seers (2003) select from McLlveen and Morse (1995), Kolcaba (1992) Paterson and Zderad (1988), Roper *et al.* (1980), Hall (1964) and Orlando (1961) provide a useful overview of the concept of comfort in relation to its historical evolution within the discipline of nursing. McLlveen and Morse (1995) argue that in contrast to the early 1900s, by 1960 comfort had moved away from the central essence of nursing to a minor strategy, focused on physical comfort and pain relief, then by the 1980's came increasing emphasis on emotional comfort. Paterson and Zderad (1988) in Connor (1993, p.26) view comfort as an overall aim

within their model of humanistic psychiatric nursing, seeing similarities between comfort and the notion of contentment, and boredom or lack of challenge as uncomfortable to humans as physical pain.

Others authors review the construct itself from a theoretical as opposed to an empirical perspective, with meaning, attributes, antecedents, consequences and uses analysed. The works of Morse and Kolcaba present comfort as a major construct for nursing, both identifying comfort as having many meanings. Morse (1992) defined comfort 'as the label for the end state of therapeutic nursing actions for a patient' and as a 'state of well-being that may occur during any stage of the illness health continuum', a definition focused on product. Later work divided comfort into the process of caring, and the procedures and tasks involved. On-going theoretical development took place through the works of Kolcaba and Wilson (2002), Kolcaba (2001, 1992), Kolcaba, and Kolcaba (1991); Kolcaba describes three types of comfort: relief, ease and transcendence, and juxtaposes these with four contexts of experience: physical, psychosocial, sociocultural and environmental. This work led to the development of a comfort framework, classed as being a mid-range theory of comfort, and the following definition of comfort evolved:

The immediate state of being strengthened through having human needs for relief, ease, and transcendence met in four contexts of experience (physical, psychospiritual, sociocultural, and environmental) (Kolcaba, 2002, p.103)

This framework incorporates the notion of an immediate experience of comfort after needs have been met. To experience a sense of relief or renewal a discomfort must exist, but to be in a state of ease or contentment a prior discomfort is not necessary. The theory is humanistic with whole person holism at its core, a perspective that holds that persons are in and surrounded by their environment but with the health practitioner retaining a role in the process (Kolcaba, 2001).

Allied health professionals provide comfort interventions, but exploration of the concept outside of nursing are rare. An occupational therapist more recently reviewed the literature to identify measures suitable for the evaluation of physical comfort in a range of settings (Pearson, 2009). A lack of consistency in measuring comfort due to the wide range of scales and tools utilized was a major finding. Studies included in the review often addressed only one or two factors that influenced comfort and did not consider the impact of symptoms, environmental variables and emotional factors. Only two measures were identified as suitable for clinical practice, the WcS-DAT (p.24) and one for wearable computers.

### ***Pain, distress or discomfort***

The Oxford dictionary (2006) describes discomfort as slight pain, in addition to descriptions suggestive of a more general nature, lack of ease and mental uneasiness, thus drawing attention to notions of both physical and general discomfort. There is generally considered to be no link between the physical pathology and the intensity of pain expressed because of the subjectivity of the pain experience for the individual (Turk, 1993); this accounts for the comment by Lamont (2003) who observed that many works appear to interchange the terms pain and discomfort.

In times past, pain was frequently untreated in this particular group of children and young people. They were excluded from pain research and assumed insensitive or indifferent to pain (Symons, Shinde and Gilles, 2008). This is no longer the case (Dubois *et al.*, 2010); there has been a significant increase in the knowledge base in this area. The impact of damage on pain mechanisms resulting from severe neurological anomalies remains unclear (Stevens, 2005), but pain from the neonatal period onward is now known to exist (Stevens, 2007) and parents are very much aware of its presence (Breau *et al.*, 2003; Carter, McArthur and Cuncliffe, 2002; Breau *et al.*, 2000; McGrath *et al.*, 1998). A recent epidemiological study of children with CP across Europe found that 73% of parents reported pain in their non-verbal children with CP over the previous four weeks (Parkinson *et al.*, 2010).

Medical conditions, common childhood pains and procedural activities put these individuals at risk of experiencing several types of pain episode (Carter, McArthur and Cuncliffe, 2002). Procedures carried out by physiotherapists can be painful (Tupper and Von Bayer., 2010; McKearnan *et al.*, 2004; Hadden and Von Bayer, 2002). Whilst, Tupper and Von Bayer., (2010) revealed home stretching exercise and passive range of movement exercise as the most painful activity of daily living carried out by physiotherapists, the topic of procedural pain remains neglected. Although findings from a recent survey has prompted paediatric physiotherapists to reflect on practice (Swiggum *et al.*, 2010). For the group of children who do not use language, non-verbal indicators from multiple dimensions have been identified, with the help of primary caregivers (McGrath *et al.*, 1998; McGrath *et al.*, 1999; Breau *et al.*, 2000; Breau *et al.*, 2001; Breau *et al.*, 2002; Stallard *et al.*, 2002). As a consequence a number of behavioural pain assessment measurement tools have developed for clinical use (Collingnon and Guisiano, 2001; Breau *et al.*, 2002; Stallard *et al.*, 2002; Terstegen *et al.*, 2003; Hunt *et al.*, 2004). Other tools have been adapted that were originally designed for a specific purpose, some unidimensional, others multidimensional

(Valkenburg *et al.*, 2010; Voepel Lewis *et al.*, 2002). Whilst some views exist which suggest parents tend to overestimate their child's pain, much of the work in this field would not have progressed without their collaboration.

Symons, Shinde and Gilles (2008) acknowledge there are problems with specificity. Behaviours indicative of increased arousal may be nonspecific indicators of distress rather than independent indicators of established acute pain (Fuller, 2001). Phan, Edwards and Robinson (2004) replicating the work of Bodfish *et al.* (2001), which used the 'Pain and Discomfort scale' to identify and measure pain in developmental disabilities, concluded that the measures possess the functional ability to measure and detect pain or discomfort. The measures could not conclusively distinguish pain from discomfort or even anxiety. This seems to suggest the importance of contextualising the experience. Recent work with adults with learning disabilities (Regnard *et al.*, 2007) was developed from the principle that specific symptoms could not be identified in people with severe communication difficulties, and the DisDAT scale these researchers developed makes no assumptions about the cause of the distress. Likewise, Ambuel *et al.* (1991), in developing an objective measure to rate levels of agitation or distress for comatose children in an intensive care setting, speaks of distress as behaviours encompassing those resulting from discomfort, anxiety, fear, and pain. This knowledge may influence situational comfort/discomfort interpretations about equipment.

## **Conclusion**

Somewhat disappointed with the sparse literature arising from the combined key word search 'comfort/discomfort' and 'adaptive equipment', I extended my search to 'sitting' and became receptive to the use of these terms in the field of chair ergonomics, or more specifically fundamental difficulties of meaning. The seat design itself affects body biomechanics, and individuals adapt. This becomes a major risk factor for musculoskeletal cumulative trauma because of improper workplace seating, with the individual then describing their experience as discomfort or pain. Individuals who have their occupational performance restricted due to the limitations imposed by equipment design in some respects have similarities to those who have to spend long periods in a wheelchair. To draw attention to the possibility of discomfort arising from equipment use, in this chapter I have discussed the problems experienced by sedentary workers and the implications of prolonged positioning for those living with a neuromuscular or neurodevelopmental disability. These individuals are often subject to additional health complications because of their immobility. I perceived that if given opportunity those who are able to use language would speak about such experiences, and that perhaps

some literature on the topic would be available. Whilst the literature was not in abundance, the topic was of sufficient importance to prompt some investigations, and for one research team to develop a tool to measure discomfort for those individuals with communicative capacity to complete. Discomfort is an unpleasant experience and causes distress, and so does pain; this meant I could not exclude a review of the body of developing literature on the topic of pain in the children who do not use language to communicate, to be precise resources, in the format of behavioural checklists, becoming available for the detection of acute pain episodes. Notwithstanding progress in recent decades consumer interest in comfort is real, the microenvironment produced by adaptive equipment attaches some physicality to the experience. Uncertainties raised over definition, about whether the absence of discomfort means comfort enhanced my receptiveness to comfort as a concept.

In this chapter, I have presented an overview of the topic comfort/discomfort and explored the link between these and other concepts. I have also examined multidimensional descriptions of the two states across discipline areas. Children's voices in the literature specifically on the topic of adaptive equipment were scarce, and whilst the main study was to focus on children and young people who were unable to use speech I perceived value in obtaining views from children who could communicate their views to contextualize my thinking in preparation for the main study. The method and findings from this preliminary phase in the study I describe in the next chapter.

## CHAPTER 4

### **A PRELIMINARY PHASE: OBTAINING PERSPECTIVES FROM CHILDREN AND YOUNG PEOPLE WHO USE LANGUAGE TO COMMUNICATE**

#### **Overview of the chapter**

In this chapter I focus on a preliminary phase in the study; its purpose being to explore the concepts in question by talking with and listening to children and young people who use adaptive equipment and who are able to communicate their views and experiences through speech or an augmentative communication aid. As children and young people when asked will talk about likes and dislikes, I perceived value in obtaining some contextual data about equipment use to substantiate a priori thoughts to be used in the main study. To gather data in this phase I used focus groups and individual interviews. The preliminary data revealed descriptive and interpretive themes, which influenced on-going review of the literature, subsequent focus of data collection and future representations in the main study. The physical nature of body part discomfort was evident in the preliminary findings but the affective insights furnish what I subsequently describe in chapter 5, as, a theoretical 'child lens' perspective.

A short overview of the methods and data analysis used in the preliminary phase occurs in this chapter, with the philosophical foundations and assumptions, methods and processes used to analyse data in the main study being the topics of chapters five, six and seven. The section on ethics in chapter 5 also expands a number of issues with applicability for the study as a whole. The current chapter also provides an overview of the procedures used to gain informed consent from those children and young people who participated in the preliminary phase of the study. To show the evolving nature of the methodology I conclude this chapter with an explanation of how the preliminary analysis advanced the main study.

#### **Preliminary Investigation: ethics, consent, access, sample and method**

Children with disabilities have often been excluded from decisions that directly relate to them (Rabiee, Sloper and Beresford, 2005). However, being aware of the successful involvement of children in assistive technology evaluations I made the decision to explore the topic with a group of children and young people who were assistive technology users and could communicate their views (Rigby *et al.*, 1996). A methodology was needed which would allow for this participation. Graue and Walsh (1998, p112) state, qualitative methods such as interviews can get children and young

people 'to talk about what they know' and how they feel. Such a methodology is consistent with the viewpoint that an individual is subjective in nature and that his or her understanding, knowledge and meaning is subjective, and emerges in interactions and interpretation with others in a given context (Flick, 2009, Greig and Taylor, 1999). In consequence, I used this framework to explore issues of comfort and discomfort with a group of children and young people who spend most of their day secured and supported in a wheelchair or other item of positioning equipment.

Project approval for the preliminary phase was obtained from a network of research ethics committees (REC) before gaining access and obtaining informed consent from any prospective participants (Appendix 3). These included a University Ethics Committee (UEC), a National Health Service (NHS) local research ethics (LREC) committee, a NHS Trust Research and Development Department (R&D) and permission to conduct the research on school premises from each respective head teacher. I also obtained Criminal Records Board Disclosure (CRB). Ethical review determines whether the rights and welfare of any prospective participants are adequately protected. Those invited to participate in research need to have full knowledge of the possible consequences and the right to refuse or withdraw from the study at any time without reason. For purposes of medical research with children parental informed consent is necessary and guidance does emphasize respect for the refusal of even young children (MRCE, 2007). Therefore, for this preliminary phase, informed consent was necessary from the children, young people, and their parents.

I did not have full responsibility for assessing competence to consent following the invitation to participate but relied on an intermediary within the school. This may have had some impact on the sampling process through pre-judging participant suitability (Scott *et al.*, 2006). However it is important that children and young people participate in research willingly and for this reason the intermediary approached each child/young person independently. This was in advance of parental contact but with a view to the child or young person making the final choice. This personal approach also avoided peer pressure influencing the child's decision to participate. Each child who expressed interest, following the initial contact, received a copy of the information and consent package (Appendix 4). I did not expect a decision straight away and asked the intermediary to give those interested the information and consent package to take home and discuss with their parents, who also received their own information package (Appendix 5). The children's information and consent forms were simpler than those for the parents but still contained the necessary information (Appendix 4). Signed consent



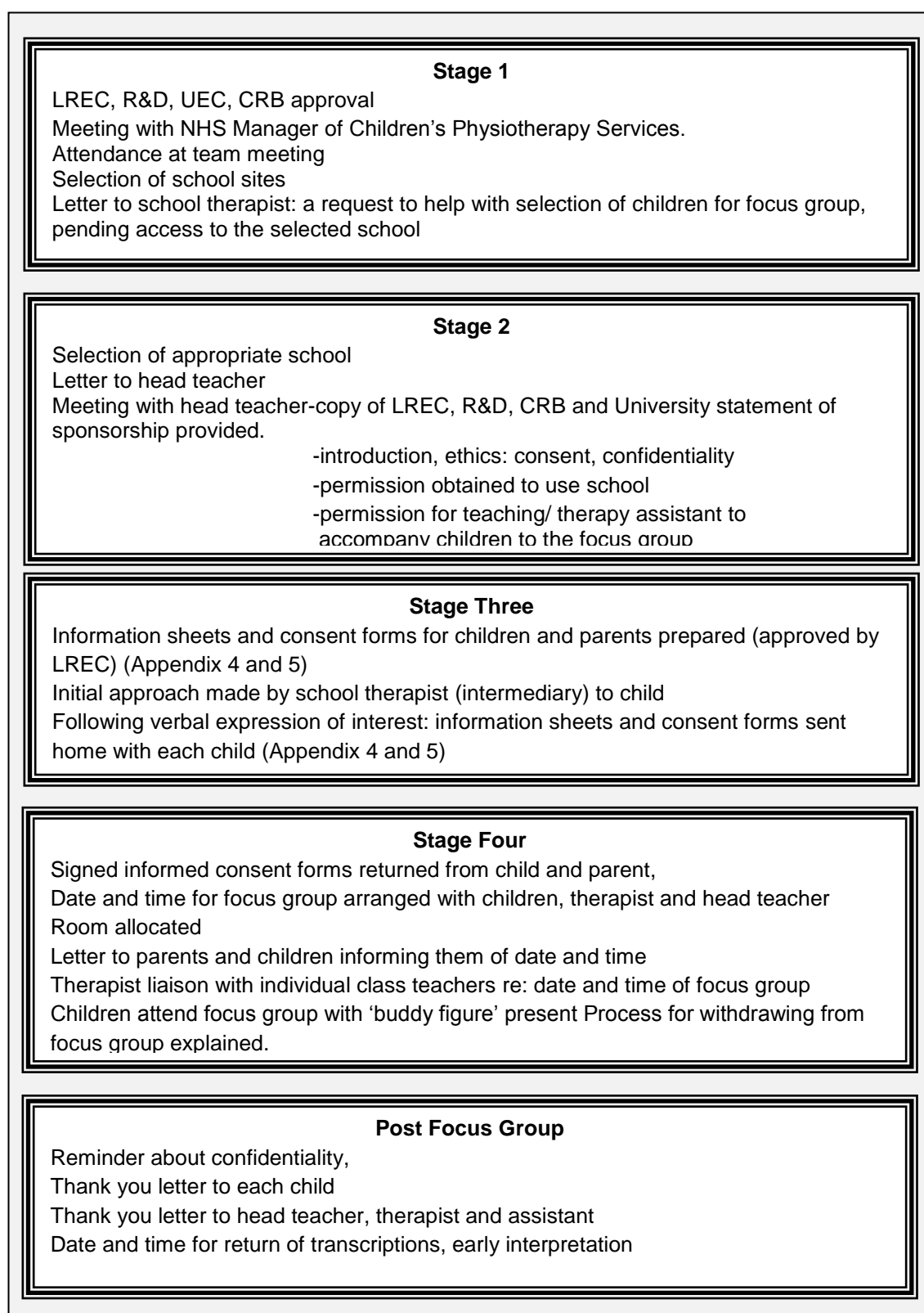
forms were returned from all participants and their parents. Figure 4.1 summarizes the process.

Convenience and judgment sampling, and, as discussed, the use of an intermediary were the strategies I used to select children and young people to take part in the focus groups or individual interviews. In the UK, inclusiveness within the education system exists and many children with disabilities are now educated in mainstream schools. The establishment of a focus group in such a setting has implications with regard to the availability of sufficient numbers of children available at one location, and consideration of transport costs if organized at an external venue. For these reasons, I held focus groups in two special schools, and then individually interviewed two young people attending mainstream school. The common factor for inclusion was the child or young person's use of adaptive positioning equipment, and ability to communicate, using language.

Information about the proposed participants in the main study and a reminder of informed consent and confidentiality issues formed the introduction and closure of each focus group as well as the individual interviews. Consent to withdraw at any time during the focus group was made possible by the use of a traffic light system, using large bright colour, paper discs, which were placed in an accessible position for each child. The red circle indicated, 'I want to stop now', and the green 'I would like to have a rest'. No child or young person wanted to discontinue and pre-focus group correspondence with the intermediary suggested eagerness and anticipation from the children and young people. One child who was very excited about the prospect of the focus group spoke about this at the beginning, 'I was looking forward to the talk coming up'. The presence of a 'buddy figure' as moderator in the interview was reassuring to the children. Bearing in mind safeguarding and child protection protocols, in negotiating access to the school with the head teacher this was something I requested as a means of reducing stranger anxiety for the children.

I called the group method a focus group; but it could quite easily be classed a group interview. Furthering an argument over the difference between group interviews, group discussion and focus groups, Flick (2009, p.203) cites the work of Morgan (1988, p.12) stating that the hallmark of focus group is the explicit use of the group interaction to produce data and insights that would be less accessible without the interaction found in a group. Little guidance was available about group dynamics, often stated to be a

Figure 4.1 Negotiating the process of gaining entry to set up the focus groups



limitation of method, where participants are children with disabilities. A section from the transcript of focus group one reveals the interplay of group dynamics (Appendix 6). In retrospect, I was guided by Patton (2002), who in contrast, to other authors states, 'The focus group interview is, first and foremost an interview. It is not a problem solving session. It is not a decision making group...'. Nonetheless, the focus group interview is an efficient, low cost qualitative data-collection technique (Flick, 2009; Patton, 2002), which is an important consideration. I was the stranger and it was my perception that a focus group would give the children confidence and security. Graue and Walsh (1998, p.114) also state that children are more relaxed in the company of a friend, rather than being alone with an adult as they help each other with their answers keeping one another on track and truthful.

The focus groups did not have the quality of uniform composition often recommended (Kreuger and Casey 2000). Ages ranged from nine to sixteen, but in addition, the mix of disabilities also represented a wider range of social and cognitive development stages within the groups. The children in the first focus group did not all have the same clinical diagnosis, but they did have enthusiasm for inclusion. Two children had CP, and three had spinal muscular atrophy (SMA). The mix of three females and two males all communicated using speech. Nonetheless, all of the children were service users in respect of equipment use. For group one, I recorded in my fieldwork diary, 'fun atmosphere, playground jokes and school friend affections'. In the second focus group, six children had CP and one the consequence of brain injury, following head trauma. There were two males and five females in this group with two pupils using an augmentative communication aid. This group progressed at a slower pace and I had to omit some components otherwise it would have overrun into lunch break. Interestingly the individuals in focus group two offered more information when I returned to member check the data for accuracy. On this occasion due to the pupils' timetabling commitments, I reviewed the data transcripts with each pupil individually, which may have accounted for their enhanced openness.

The focus groups and interviews took place during the school day and on school premises. Before the children arrived I arranged a meeting with the buddy/moderator figure to discuss their role, talk about anonymity and confidentiality, explain the props I would be using, and request their help to match the name signs I had prepared. At the beginning of the focus group, I introduced the children and young people to the 'traffic light system' and asked their permission to use a voice-recording device. Everyone listened to play back of his or her voice before the interview commenced, with the earlier events of each person's day used to facilitate this process. I made every effort to

present myself in a friendly and reassuring manner and took the lead from the children with regard to appropriate facilitation of peer interaction. Questions phrased in a straightforward manner followed the pre-prepared schedule (Appendix 7), which I interspaced with activities involving props, and pictures. I did not introduce the word discomfort until first mentioned by the children. In my reflective diary I wrote, '... the introductory question about transferring into the wheelchair opened up perceptions of not sitting correctly'. Excluding preparatory and necessary introductions, each focus group lasted approximately forty-five minutes, with allowance made to include a short break with drinks and biscuits provided.

Following transcription of the focus group data, I returned to each school in order to check for consistency. For focus group one, there was an interval of four weeks due to school holidays and on this occasion I had to use a different moderator/buddy figure; this meant repeating the anonymity and confidentiality procedures. Again, I felt the need for a schedule. For this I transcribed quotes, using large size font on to coloured card and held these up to start discussion. As a further means of conveying the importance of privacy and confidentiality following the focus group, I let the children decide on their own pseudonyms, also supposing this to be a good way for them to gain closure. Unfortunately, this did not go as planned; two of the five children in the first group decided they wanted to use the same name as another child within the focus group or the authentic name of another member within the group. The children may have lacked full understanding of this issue or alternatively, simply liked the name suggested. No new information arose from group one except for additional observations I recorded in my fieldwork diary. One such observation related to the daytime temperature and humidity on my return visit and another to the frequency of requests for positional change during the interview. Within the forty-five-minute period, one young person asked for re-positioning within the chair four times, but only asked once in the initial interview. The children from focus group two individually expanded their responses on my return visit.

I also carried out individual interviews with two young people attending mainstream school. Although choice of home or school was available, the interviews took place in a room set aside for healthcare needs within mainstream school. Fewer props were necessary for the individual interviews with these two young people as they were able to explore topics in greater depth. The data for subsequent analysis was in the format of text from transcription of the interviews, body charts and field notes. Data analysis for this preliminary phase I outline in Table 4.1, whereas analysis of data from the main study I describe at length in chapter 7.

Table 4.1 Preliminary data analysis

Transcription of interviews, reading, numbering of each line and page
Initial margin colour coding of participant quotes and fieldwork notes, based on interview questions-production of descriptive codes
Second reading - conceptual codes added, memoing
Clustering of codes and cross checking
Respondent validation
Examination of grouped data, exploration and interpretation alongside existing theory

## Findings

Due to personal and contextual influences, the factors influencing comfort and discomfort for each child or young person in the preliminary phase varied, but some connecting and distinguishing features emerged which I have summarised in Table 4.2

Table 4.2 Descriptive and interpretive themes: preliminary phase of the study

Words to describe the experience
Discomfort of body parts
The relationship with others
Additional personal and environmental influences:
-Aesthetics
-Need to 'lounges' and relax, movement versus restriction
-Distraction

## Use of words

The children in the preliminary phase could communicate their experiences using words akin to comfort/discomfort as part of their vocabulary and to this extent were confirming or disconfirming knowledge as it existed in their world (Table 4.3). The following sequence from focus group one describes its introduction and inclusion. Helen was asked about her early morning transfer into the wheelchair:

Int: when you got in your chair this morning did anyone have to adjust your position once in the chair?  
Helen: yes always have to  
Int: you always have to adjust your position, so what happens?  
Helen: it gets uncomfortable and sore

Int: so when you actually get in the chair you know that you're uncomfortable and sore, and what do you ...?

Helen: yes, I tell my mam that I need to be moved (FG1p.3)

Table 4.3 Comfort/discomfort words and phrases

Comfort	Discomfort
It's just comfortier	I just feel uncomfortable
Comfy	Uncomfortable to have the straps on
Comfortable sometimes	Shooting pains
Until I start getting uncomfortable again	Sore
I will probably try and make myself comfortable but doesn't go very fast	Hurts my bottom
You lie back and that makes you feel a little more comfortable	My neck hurts as well
I sort of move myself to get comfortable	Sometimes I just get stiff in all my body parts, So I' m just glad I am out of the chair
I repositioned myself this morning alright after that	Discomfort being in pain all the time
Comfier	Pressure
I have a stretch when my back hurts it helps to calm it down	I've got bad hips, I get sore if I sit in one position too long
Try to move my body away from it	It get uncomfortable and sore
Slump forwards	It's very uncomfortable
I try to stay in my bed longer	Bum
I probably lean which is not good for my posture	It takes three hours to get comfortable, but then I may not proper comfortable

Some words in Table 4.3 may be described as sensory; others affective; the word pain also appears. Translating feelings into words, which would differentiate pain and discomfort, is difficult, as overlap exists in word definitions (Closs and Briggs, 2001). Due to varying social and cognitive development of the children and young people this is not something I pursued in the focus groups, although Beth, an articulate pupil attending mainstream school stated that for her 'discomfort was being in pain all the time' (Table 4.3). Recurrent musculoskeletal pain is prevalent in children, young people and adults with CP, and neuromuscular diseases (Engel *et al.*, 2009; Engel *et al.*, 2005; Jahnsen *et al.*, 2004; Albresch *et al.*, 2002). Therefore, these descriptions might be indicative of key characteristics of a particular painful secondary condition. In

contrast, Jensen *et al.* (2005) identified environmental stimuli as amongst other causes including prolonged sitting, static positioning and the wearing of orthotics and splints as factors causing pain to worsen. Whilst Closs and Briggs (2001) confirm overlap of these terms in patients undergoing orthopaedic surgery, their findings suggest descriptions of pain tended towards an internal phenomenon, discomfort being more frequently related to environmental stimuli. A phenomenological exploration of pain in persons with physical disabilities, by Dudgeon *et al.* (2002) is more cautious, concluding pain as having 'multiple locations, distinctive descriptions and different implications, often a mystery having unclear causes and consequence'. Table 4.3 accounts for environmental stimuli, but data also revealed the possibility of known painful musculoskeletal conditions.

Inspired by pictures used by Boldingh *et al.* (2004), who developed the Pain Assessment (PAICP) instrument to measure hip problems in CP, I showed the group clip art and magazine pictures of situations that might be painful, and those likely, to be of a milder nature, to prompt discussion for example, a picture of a boy sitting on the ground crying. Graue and Walsh (1998, p.12) refer to the work of Corsaro (1985) in suggesting that children are able to invent, within adult created contexts, their own sub contexts, which most often remain invisible to adults but are most visible and salient to other children. The extract below vividly portrays this, whilst at the same time giving some understanding of their appreciation of either the intensity or affect of such experiences.

Rachel: That one's crying, flying star coming off  
 Mark: what happened to the boy- did he fall over ...?  
 Helen: maybe a car hit him  
 Laura: would have been dead if a car had hit him...  
 Helen I think someone has dropped a rock on his toe  
 Mark: he's a doctor. Has a headache  
 Rachel: I get sore head...noisy boys in this school, all the girls are quiet  
 Int: do you think someone who has a sore head, is worse than someone who has fallen over?  
 Laura: can take pills.  
 Rachel: can take two paracetamol for that?  
 Mark: is the doctor going to stitch his leg up.  
 Laura: what if he can't walk. (F1p13)

### **Body parts**

Findings locating discomfort to several body regions was expected (Table 4.4), as pain as a topic area, pain distribution on body parts, and musculoskeletal pain has already been investigated in children and adults with CP who have expressive communication.

In the focus group and interviews I used body charts for the children to locate their discomforts, and the words used found in Table 4.4

Table 4.4 Body part discomforts

The bottom of my back	Side of my body
Hips	Bottom
My back	Soreness in the creases
Under knees	Just my bum
It's on that side more	My neck
Hip, legs, bottom of my back	It was digging in [the side] making blisters

Jahnsen *et al.* (2004) investigated musculoskeletal pain in 327 adults with CP, and the findings revealed a high incidence of back pain with the majority of respondents reporting pain from more than one part of the body. Likewise, 67% per cent of the 93 adults surveyed by Schwartz, Engel and Jensen (1999) experienced long-standing pain involving more than one body area. It was out with the remit of the current study to make a judgment about cause. Nonetheless reported experiences were affective. Beth describes her opportunity for repositioning

...sometimes I am more uncomfortable after I have been to the toilet. Sometimes I am more comfortable if I just sit in the chair longer, because you get used to the pain, when you get moved the pain goes back to the beginning and it gets worse again. You know there is a sharp stabbing pain you just try to sit still without moving,

The secondary health problems existing in this group of children would suggest their bodies are prone to compressive forces in regions of the body other than the buttocks, although it is this area, which often receives attention due to the higher risk of pressure sores occurring in this region in wheelchair users. Those in the study had good pressure relief cushions and therefore buttock skin breakdown was not a problem. Although a blister due to pressure on the elbows was a topic.

### ***The relationship with others***

Two children in the preliminary study could do assisted transfers, whilst the others were dependent on caregivers for gross postural position changes. All except these two individuals spoke about directing others to do this for them. The requested adjustments, at times, were small but considered a necessary pre-requisite for comfort. They had control over the nature and intensity of repositioning. In the words of one young person, followed by one of the younger children



Straight away, I would ask [for] my bum to be lifted and pulled right back into my seat and then pulled forward by the leg (FG1)

I sometimes need a push over (FG1)

During the school day Laura informs the teacher if she needs to move, which is usually a couple of times every hour and asks to have the straps loosened, as these and the lateral trunk supports can be uncomfortable. The accessories are less of a problem for Helen, but she still asks the teaching assistant. She said, 'I've got bad hips; I get sore if I sit in one position too long'. Helen has a tilt feature on her powered wheelchair but still needs to have her bottom adjusted. Mark also asks the classroom support assistant to adjust him about twice an hour. This may vary from day to day. For example, I noted Mark only asked the buddy/moderator to adjust his posture once during the interview, but on the day I returned to member check he requested four adjustments. Another child adjusted three times, but not at all during the focus group. The ambient summer temperature during the 'member checking' event was high, which may have accounted for the difference. During focus group two, I stopped the discussion to allow for adjustment of Anna's posture, but Jackie, Graham and Colin and Annie could make some within-chair adjustments themselves, which became more obvious on my return visit.

A study by Skar (2002) found that children's relationships with their teaching assistants varied, younger children seeing the assistant as part of their life in contrast to an expressed wish for independence from older pupils. Beth explains

My mum has known me for ages, she knows what I want her to do, so I don't really, she just knows what I want her to do and I don't really have to ask her but, if I do she will do it for me. It's different for different people, my mam does it the best cause she's done it for the longest, but other people do it differently so when I go to respite I am never comfortable because they don't do it right. I think it's because I don't like asking for things to be done for me, because I am independent. But I will ask them and say can you pull me this way, but then it's different, and there, they are only allowed to do it certain ways for health and safety.

In preference Beth tries to adjust her own posture to get comfortable but in the process leans, which she admits is not good for her posture. This is in contrast to Mark, one of youngest children in the focus group. I asked Mark if anyone adjusted his position in his chair:

Mark: em yes... [name of assistant]....my one to one

Int: [name of assistant] your one to one, and how often do you have to ask [name of assistant] for adjustment?

Mark: a couple of times an hour

Int: why do you think that is?

Mark: just feel uncomfortable all of your body, your hips my back

### ***Environments and personal influences***

As compared with school, home is an important place for relaxation, which, for a number of children and young people in the preliminary phase, meant freedom from the restrictions imposed by equipment during the school day. They spoke about this time of day, with not dissimilar views to the general public; the need for time out addressing needs other than postural support. The activity introduced to stimulate discussion about comfort/discomfort vocabulary also reaffirmed the children and young people's desire for relaxation

Mark: can I order the pink one is that a beanbag?

Rachel: I like that middle one.

Mark: like the bench or the middle one.

Int: why do you think you would rather have the bench?

Chris: I could try and sit on and sit outside

Rachel: we use to have one of them but it was uncomfortable

Gemma: I think I would like the armchair, I would take the comfy armchair

Mark: I would take the green one at the bottom

Int: You would take the green one

Mark: and bring it to school and then I could have a rest when I am doing my lessons

Int: so what else do you like about the green chair?

Mark: it lies back

Int: it lies back, would that make you feel better

Mark:yeh

Rachel: I like the pink one as well

Int: Why do you think you like the pink one?

Cause its pink. I would be more comfortable

Gemma: it's the most squelchy, squashy and soft

Int: What about you Helen , can you say anything about those chairs?

Helen: I like the middle one

Int: you quite like the middle one; do you know why you quite like the middle one?

Helen: I don't know

Rachel: I like the middle one better though, you can have a lie down and watch telly: What's the green one made out of?

Chris: plastic

Chris: plastic, metal legs

Mark: Rachel will fall asleep

Int: it's probably made of canvas or vinyl

Gemma: Rachel will fall asleep

Rachel: I would fall asleep if I had one of them ones

The children in focus group two use not dissimilar words: 'it looks comfortable', 'you can lie back', 'think it would be comfortable, because you feel you could stretch out'. The need for aesthetically appealing wheelchairs has been recognised (Cox, 2003;

Turner, 2001; Aldersea, 1999); however, the props I used to initiate word discussion were pictures of chairs, not wheelchairs or adaptive seating. Nonetheless, the immediate impact of appearance was obvious. The children and young people made value judgments about the chairs. These 'aesthetic moments of experience' (Duwell, 1999), and perceptions offered were similar to the views of the ergonomist Helander (2003). He argued that consumers are guided more by aesthetics than longer-term ergonomic features, and in a series of studies found that users could distinguish between parameters that relate comfort to a sense of well being and aesthetics, and discomfort to biomechanics and fatigue factors, not ergonomic features (Helander, 2003; Helander and Zhang, 1997). In the study by Rigby *et al.* (1996), 84 children helped guide the design of a paediatric seating system by participating in a paediatric seating day. Fifty were users of adaptive seating. The participants were asked to give preferences about the specific features of adaptive seating systems and the protocol developed was found to be reliable and valid for obtaining the perspectives from children with physical disabilities. Appearance was important for Beth. She likes 'small and compact, something that holds you up but probably you could not see the support'.

An ability to control a powered wheelchair in varying environments of use was a characteristic of the participants in the preliminary phase but this would likely vary from those in the main study who may have insufficient skill to reduce the safety risks for self and others (Nylson and Nyburg, 2003). A powered wheelchair can maximize human performance (Kuckler O'Shea, Carlson and Ramsay, 2006) and, within school, aid social and curricula participation. Annie and Anna from focus group two said they could get 'all over...' Those school pupils in the preliminary phase clearly gained from this, some choosing to remain in the chair after school so they could get around. Mobility was clearly important. This may offer some distraction from bodily discomforts.

Distraction is a recognised, theoretically sound strategy, for coping with pain-produced distress (McCaul and Mallott, 1984). In the paediatric population, empirical work in this field has focused on distraction following acute pain episodes. A critical review of distraction for paediatric immunizations by DeMore and Cohen (2005) concluded that distraction was clinically effective, but stated those requiring an overt behavioural response from the child and multiple sensory modalities may be more useful. For any child or young person distractions pack the school day, but empirical health care work for children with disabilities is still limited in this area.

Katy and Beth who attend mainstream school coped differently with discomfort. Beth never asks for a positional change during a class. I asked whether that was because

she was concentrating on her lessons. She thinks about the discomfort but does not ask and prefers to wait until break for adjustments. Katy appears to have more control of her posture if she is not restricted, but Katy would leave class.

Katy: I used to wear it, but I forget to put it on, and then it is too small as well, when it is around it is too tight and stops me from being able to move forward

Int: The lap belt really stopped you from being able to lean forward.

So you like to come forward, you like to lean forward,

Katy: Yes.

Int: And you can get back up yourself. And it is important for you to lean forward. When do you think you need to lean forward?

Kay: To make me comfortable in the chair, when I am sitting around and I am sick of sitting like this I lean forward.

## **Conclusion**

In this chapter, I have discussed a preliminary phase to the main study. I located the research design within a qualitative framework and talked to children and young people with capacity and enthusiasm to communicate their views. I was interested in their experiences but with awareness that the characteristics of the children and young people proposed for the main study would be different. Limitations were evident in the sampling but strength was that all perspectives were valued. The findings were in line with existing research in the areas described.

The children and young people described location and used words akin to discomfort as part of their vocabulary, with equipment at times contributing to such experiences. For them comfort was desirable. Whilst using adaptive equipment these children and young people had some control of their environmental mobility, usually by means of a powered wheelchair. They also had the ability to use language to direct others in various ways within different environments of use. This would differ from the prospective participants in the main study. One emerging theme, that of enabling the individual to rise temporarily above certain degrees of discomfort, gained greater meaning as data collection for the main study progressed.

In summary, the contextual findings from the preliminary phase and the extended readings of chapter 3 gave direction to the inquiry enabling meaning making surrounding the concepts in question to progress. In chapter 5, I examine the philosophical foundations and assumptions, which influenced the methodological decisions made throughout the duration of the study.

## **CHAPTER 5**

### **THE THEORETICAL UNPERPINNINGS OF THE PROCESS OF THE RESEARCH: THE NEED FOR AN ILLUSTRATIVE METHODOLOGY**

#### **Overview of the chapter**

In this chapter, I examine the philosophical foundations and assumptions, which influenced the methodological decisions made throughout the duration of the study. The broad enquiry questions influenced the research design. These arose from a critical, reflective analysis of every day practice, triggered by a significant event – the expression of some thought provoking words by a father, who felt his child was uncomfortable and inhumanely strapped into his wheelchair. Personal growth had come about because of this significant experience; unquestionably, my clinical practice became more person-centred. This orientation guided a search for methods appropriate to placing the children, notwithstanding their communication difficulties, at the focal point of the research. I wanted to give some consideration to feelings that are often hidden by impaired communication, to give some ‘voice’ to these children and young people, and thus provide some vision of the human context surrounding equipment use. An experiential awareness of interpersonal influences and social context as influencing experience compelled me to search for an integrative approach in order to gain inclusive understandings of the phenomena.

Inextricably linked are ontological and methodological commitments, and as I set about situating the research within a paradigmatic framework a set of three representations guided the location of underpinning theoretical perspectives against the backdrop of qualitative research. I refer to these as three theoretical lenses as each continued to inform the evolving research strategy: a child lens, a practitioner lens and a researcher lens. There is an absence of simple lines of demarcation, but by the end of the chapter, I will have charted a journey starting from philosophical considerations, through those of methodology, towards a discussion of case study as the research strategy. In raising questions as to what issues were important to examine, these lenses indicate where I positioned myself in this research.

First, under the heading of child lens comes examination of congruency in ideals, values and the proposed methodology between self and children with complex needs. Here I give an account of the lived body as the mode of being in the world, introducing the concept of embodiment. Next, the aim is to sense the power of professional knowledge. I depict meaningful connections between knowledge, clinical reasoning and

expertise. This discussion gives prominence to my own personal knowing to justify the use of person centred practitioner judgment as guiding my methodological decision-making. Such philosophical awakening inevitably embeds itself into the research design. Here I examine the possible contribution of different approaches before arriving at case study design as the approach of choice.

### **Child [young person] lens**

Regardless of difference, all children hold a very special place in society (Greig, Taylor and Mackay, 1999). Children with PMLD have all the needs of any child, intrinsic worth and unique identity as people of value (Sullivan, 1990), irrespective of their cognitive and physical impairments. However, in the daily management of children with complex needs, care can often be about physical care based 'around' the child (Roberts, 2005, p.254). This can often become routine, determined by numerous contextual influences. The multi-professional team, the parents and other caregivers are adults, knowledge holders, proxy reporters, decision makers, and in the current situation interpret comfort/discomfort status.

Most people have experienced feelings of pressure in the buttock area after sitting for a prolonged period. To ease this discomfort people fidget. A simplistic view, but nonetheless leading to the framing of my child lens was the notion of the child's need to be free from this discomfort. I wanted to consider what it felt like for them and what this experience meant for them? They may lack the cognitive sophistication to convert discomfort experiences into expressed language, but this should not mean their communicative signals are less worthy of inclusion. There was awareness that I would still have to impose some theoretical categories onto the child or young person's true experience, but finding a methodology to place their experience at the centre was the intention. In developing the methodology, fundamentally, I saw the children and young people experiencing comfort or the distress of discomfort bound up in the social and cultural milieu of everyday living.

In physiotherapy research, the body is the obvious location for scholarly inquiry. Initial direction was toward a traditional scientific approach, which has greater focus on physical and biological mechanisms, and emphasis on empirical data collection and discovery of cause and effect relationships (Creswell, 2007). I can relate to using elements of this epistemology in practice, as clinical decisions made by physiotherapists are traditionally in the realm of impairments and activity limitations and the focus of research often the effectiveness of treatment interventions. The literature review for this study, with a focus on biomedical knowledge, had revealed a

predominance of studies of this nature with a priori use of theory. For example, constructs, which focus on the inner qualities of a discomfort experience and the mechanical and biochemical processes contributing to the viability of body tissues. Similarly, this approach locates the impairments allied to childhood conditions in a corporeal domain. Therefore from a paediatric physiotherapist's perspective, biological reduction alone provides grounding for interventions, where the emphasis is on physical body.

Physiotherapy researchers using this perspective use logical and rigorous methods to collect data, which are often quantitative in nature and underpinned by a worldview grounded in post-positivism (Plack, 2005). This paradigm maintains a positivist stance on objective reality, yet accepts that verification of all statements is not possible through direct observation. In dealing with human behaviour, objectivity in totality is unattainable, and multiple perspectives are possible. The findings from several of the studies documented in chapter 2 and 3 reveal isolation and measurement of discrete factors. The kinds of laws and principles to account for events are assumed universal, abstract and fundamental, an orderly reality behind the complex and changing world of real humans and their behaviour (Slife and Williams, 1995, p.141). Reduction in the minds of some scholars is essential for scientific explanation. Although not absolute, I could not deny some belief in this system. I had after all considered measurement of the observable behavioural expressions of a comfort/discomfort experience. However, the metaphysical explanations afforded by such a traditional linear scientific approach make it difficult to retain the uniqueness and individuality of human beings (Slife and Williams 1995, p.143). For health care professionals in practice, conceptions of mind-body dualism appear erroneous. Yet, Van Hooft (2006, p.95) makes the argument that a more vague form of dualism may exist. This, he argues, might occur when the time available to perform the concrete aspects of caring for a person is reduced, and the health professional therefore simply focuses on the needs of the physical body. This is also, as argued by van der Riet (1997, p.100), a potential consequence of the use of technology in health care which could include adaptive equipment.

From a post modern perspective, Slife and Williams (1995,p.161), in questioning whether an alternative to traditional reductionism rules out biological influences, argue that the biological processes are part of the experience of being human, remain important and need to be understood. In considering traditional approaches, Van Hooft (2006, p.106) questions whether compelling empirical or logical evidence of biological reduction exists. He states, 'to care for the body is to, inevitably, care for the well-being of the whole person', insisting that health practitioners are not wrong in focusing

attention on the body as long as they adopt a non-dualist approach, and accept that the body is the 'locus of full human functioning of the person in social communication and definition'. To do this the practitioner requires genuine commitment, thereby implying recognition that the body is, in its turn, the authentic presence of the patient. In this study, I did not intend to set aside the child or young person, or be unmindful of the person within the body.

A number of authors drew my attention to the writings by philosophers of the 20<sup>th</sup> century, the study of phenomena and the philosophy of phenomenology. These afforded understanding of the relationship between the 'human being' and the 'physical body', therefore enabling the assumptions underpinning my child lens to be more understandable. Of particular interest were those who had explored the social and cultural representations of phenomena of consequence to the physiotherapy profession. Pain was such an example; a phenomenon described by Kugelman (1999) as personal, cultural, mental and bodily. The distinguishing feature of phenomenology is 'its primary concern with the nature and meaning of experience as it is lived' (Madjar, 1998, p.28). The human being is viewed as an intentionally lived relation, engaged in and engaging social and physical context. Madjar (1998), a nurse, studied the lived experience of inflicted pain in the context of medically prescribed treatment for patients recovering from burn injuries. Winance (2006) explored pain, disability and rehabilitation practices in persons with a disability following a road traffic accident or neuromuscular illness. The meanings of such pain for persons who endured it became the focus of exploration. It was, however, from the phenomenological methodological reflection of 'being a human being' and the strategy of thinking about a human being as an essentially cultural phenomenon from which insights developed. These authors refer in particular to the work of Maurice Merleau-Ponty (1908-1961).

Using key texts written by the 20<sup>th</sup> century philosophers, Edmund Husserl (1859-1938), Martin Heidegger (1889-1976), Jean Paul Sartre (1905-1980), Maurice Merleau-Ponty (1908-1961), Levinas (1906-1994) and Derrida (1930-2004), Glendinning (2007) has recently explored the landscape of phenomenology. He describes different ways in which each philosopher has responded to and transformed the legacy of phenomenology. He gives credit to Husserl for introducing the study of lived experience. Husserl believed a scientific approach was necessary to bring out the essential components specific to a group of people. However, it was Martin Heidegger who reawakened the question of being, using the term 'being-in-the-world' to emphasize an inability of humans to abstract from the world. This perspective which



places the body as the basic mode of 'being in the world' is a different mode of engagement to a present-at-hand mode which characterizes empiricism and rationalism. Heidegger proffers much debate against the metaphysical models of persons. The ready-to-hand mode signifies practical understanding and a radically different way of knowing (Slife and Williams, 1995).

For Merleau Ponty (Glenndinning, 2007, p.134), bodily presence 'is not an object of the world' but on the contrary, 'our means of communication with it'. The analysis of self-experience begins not with self-consciousness, nor even with Deasyn, as Heidegger understands, but with the facticity of existence of the living human body. The body as an embodied being is subject to perception and consequently access to the world (Madjar 1998). In this notion of embodiment, an individual may have had the neuromaturational processes interrupted because of damage to the developing brain yet they still have the disposition to develop as a person. Human beings have a physical body and experience the world with and through their bodies (Slife and Williams, 1995). The person, through this body, is visible, audible, touchable and noticeable, and the means through which he or she develops a sense of self and comes to know the world, and according to Papadimitriou (2008) act in their lives according to meanings that have become familiar.

To move beyond mere physicality, however, some form of relationship with another person is required (Van Hooft, 2006). This establishes the body as 'loci of being-for-others', which Van Hooft (2006, p.68) borrows and adapts from Jon Paul Sartre to indicate a further facet of being human. He states that our bodies 'are centrally implicated in our being for others and are therefore essential and constitutive elements in our being social, communicative, expressive and human.'

It is possible to be physically near someone and not be aware of the pain that person may be experiencing (Scarry, 1985). To gain control over discomfort it is therefore necessary to give voice to this invisible and inexplicable phenomenon. This has implications for the children and young persons with no language because language is one of the culturally learned ways of being in the world with others. Scarry (1985, p.4) makes another important point, suggesting that physical pain in some circumstances can actually resist or destroy language, bringing about a state anterior to language, to the sounds and cries a human makes before language is learned. In this situation, those who are not themselves in pain but who speak on behalf of those who are bring the language of pain into being. Madjar (1998, p. 40) suggests there are difficulties, one of the most important being the inability or unwillingness to hear the expression of

pain from the person in pain. To avoid misuse of power an existential presence in a therapeutic relationship is required. This according to MacLeod and McPherson (2007) involves availability, openness and giving to others so a sense of value and respect are communicated. In children with PMLD and persons with dementia, the nurturing of relationships is important as this helps maintain a connection between the person, their social world and their personhood. Kitwood (1997, p.8) describes this as the standing or status that is bestowed upon one human being by others in the context of relationship and social being. It requires recognition, respect, trust, and the capacity to truly see the other fundamentally as a person, and then speak on their behalf. In support of personhood for children with PMLD, and others who lack the capability of reason, of self-awareness and self-determination because of their low level of cognitive functioning, Hogg (2007) proposes that their very presence affects others interpersonally, which is an assertion of personhood in a social context.

This mode of understanding of the body afforded by the philosophers and researchers enables the portrayal of my child lens to be more understandable. Each child and young person has grown and developed in a social world, formed relationships with others, becoming distinct persons. In consequence, the experiences of the children and young people and their expressive behaviours form and inform the context of the comfort/discomfort experience. There is a complex interplay between the lived body of the child or young person, the adaptive equipment, the environment, the culture and person characteristics. The children may be less active, and unable to engage in dialogue, but nonetheless each is an embodied being in relationship with others. Discomfort and comfort warrants understanding in its lived body context. These phenomenological insights have epistemological implication for subsequent decision making in respect of methods for gathering data.

### **Personal and professional practice lens**

Research is done by people and it is necessary to understand the people who create it or construct it (Reed, 1995, p.47)

Currently, I have a full-time lecturing role in higher education and this categorizes me as an academic. Evidence-based practice and research informs my teaching. As an academic, I seek to contribute to the development of physiotherapy, but as a former paediatric physiotherapist I sought generation of knowledge through practice. The notion of practitioner researcher evades my status, as I am no longer part of the world I intend to research. Yet there is a career life history within that culture, which is impossible to ignore. I chose to pursue a career as a paediatric physiotherapist in the

field of special education. Both professional cultures in consequence part shape the ontological assumptions described in the first lens. This hybrid crisis of identity ultimately led to the second of my three representations, and the question of how I substantiate and make explicit an epistemic understanding of my practice knowledge. This was a major influence on the research enquiry.

Hybrid is one of the researcher positions in the continuum conceptualized by Reed and Proctor (1995). In practitioner research, it is the role adopted by practitioners undertaking research into the practice of other practitioners. This contrasts with the 'outsider', a researcher undertaking research into practice with no professional experience, and the 'insider', a practitioner who undertakes research into his or her own and their colleagues practice (Reed and Proctor 1995, p.10). In this research, I retain hybrid identity as there are similar aspirations to practitioner research. In the 1970's, adaptive seating and postural management evolved in response to a need identified in practice, and not from earlier research as this did not exist. The literature of the time reporting the needs of the children and young people would now be labelled as anecdotal and subjective. Valued appreciation came from contextually generated knowledge. In the 21<sup>st</sup> century, service provision and resource implications come under scrutiny. If supply were in jeopardy, there could be protest from families; adaptive seating changed lives and changed professional practice, made possible because of knowledge generated in practice.

To develop a strategy to authenticate an unexplored dimension within the field of postural management was my aim. Meerabeau (1995) argues that practitioner knowledge informs research by guiding choice about research questions and strategies. However, simply stating professional experience guided the development of research strategy was insufficient; after all, some aspects of practitioner knowledge remain tacit. To explicate practitioner knowledge it was necessary to delve more deeply into the different forms of knowledge that arise from, and become integrated into practice, thus giving credence to my own practice epistemology.

The evidence concept of natural science, which advanced toward the end of the 1990s, is not superfluous. It has had a significant positive impact on the physiotherapy profession (Jones *et al.*, 2006). But by then, I already had some appreciation of the broader scope of professional practice utilising a biopsychosocial reasoning and practice model (Jones, Jensen and Edwards, 2008). In the context of special seating, there was no 'ideal' chair; the potential to provide postural management programmes existed, but successful outcome was only achievable by working in partnership with the

children, parents and other interdisciplinary team members within health and education. The world of practice was complex and forever changing. Settings, circumstances and other perspectives, including resources, influenced the clinical decisions I made and the outcomes evaluated. There was considerable uncertainty, and in such situations, dimensions other than evidence-based practice (EBP) influenced my clinical reasoning.

Theoretical understanding of clinical reasoning continued to advance during this same period, and now in the 21<sup>st</sup> century core dimensions are more explicit. For physiotherapists clinical reasoning is a 'lived phenomenon, an experience, a way of being and a chosen model of practicing' rather than simply a process (Higgs and Jones, 2008, p.4). The core elements, knowledge, cognition, and metacognition remain, but viewpoints have expanded to place more emphasis on patient-centred care as the context for clinical reasoning (Higgs and Jones, 2008, p.5). This sits well with my own worldview, as it is the desirable approach for those working with children and young people with complex needs and a point of centrality as part of the UK NHS reforms. Jukes (2006) places the notion of person-centeredness alongside a contemporary learning disability context, arguing that the cohesiveness of such an approach occurs because the person is at the heart of communication, along with an attitude of value, equality, respect and partnership. Being person-centred means getting closer to the individual, and is achieved through the person's authenticity (McCormack, 2003).

The experienced practitioner will use cognition to process 'clinical data' and metacognition as a bridge between knowledge and cognition (Higgs and Jones, 2008, p.5). They draw on a strong discipline specific knowledge base, comprising propositional knowledge but will also use non-propositional knowledge derived from professional and personal experience. This is the invisible and tacit aspect of advanced and expert practice, which proponents advocate as the knowledge beyond science required for quality client centred practice (Paterson and Higgs, 2008). Reporting the findings from a qualitative study Gwyer (2007, p.86) describes how on the path to expert practice, paediatric therapists learn from each clinical encounter. She states:

...they quickly redefined their roles with their patients and then broadened the scope of knowledge they need to perform these roles. They deepen their physical therapy content knowledge, transforming it into meaningful clinical knowledge through constant analysis; they began their practices in single disciplinary roles with limited and prescriptive clinical decisions and progressed into interdisciplinary

and multidisciplinary roles requiring sophisticated clinical judgments. Very little had gone unnoticed in their years of practice.

Their relationships with children, young people and families develop and their individual virtues strengthen because they base their practice around skilled interactional and intrapersonal processes and engage in much reflection. Compassion, sympathy and empathy have a central place in the understanding of humane and ethical treatment of patients, and the significant event which triggered this research has in the words of Jensen, Resnik and Haddad (2008, p.133) prompted me to 'think out loud' about the phenomena of comfort and discomfort and what this means for the children and young people.

The traditional concept of knowledge is associated with the Platonic (400 BC) definition of episteme, from which the word epistemology derives, and long considered as that which is generated from theorization in a world of external objective reality (Higgs, Fish and Rothwell, 2008). This, since the time of Aristotle (300 BC), is contrasted with '*phronesis*' representing practical knowledge or wisdom (Gustavsson, 2004, p.36). In the 19<sup>th</sup> and 20<sup>th</sup> century, philosophers William James, John Dewy and Charles Sanders Pierce theorized about practice, but with expectation that abstract knowledge disseminated via experts added to practical knowledge. Acknowledging the works of, Gilbert Ryle, Michael Polanyi and Ludwig Wittgenstein, discussion of this perspective by Gustavsson (2004) was helpful. Different perspectives on the meaning of knowledge he argues can be broadened and applied to the goals and practical problems faced by practitioners. Using the terms proffered by Ryle, 'knowing how and knowing that' Gustavsson (p44) states that when a practitioner does something with an intention and know what they do, they develop practical knowledge. The wisdom gained through this experience resides in what Michael Polanyi describes as the tacit dimension. This is knowledge that practitioners have but known in a direct practical way and not stated as a formal theory. Whilst Wittgenstein distinguished 'that which can be said and that which is beyond words' as influential in regard of exploration into the nature of practical knowledge one recurring question as stated by Ryle (Gustavsson 2004, p.44) is whether tacit knowledge must remain tacit or if verbal expression can be given to it through reflection. For practitioners in practice, the views of Schön (1991) became influential following his study into the day-to-day work of a variety of practitioners. Schön proposed that implicit or tacit knowledge develops because of the person's ability to think about or reflect upon an event as it is taking place. Thus, through action and reflection practitioner knowledge develops and guides future action comprising daily practice. Schön (1991, p.353) urged professional practitioners to 'discover and

restructure the interpersonal theories of action which they bring to their professional lives'. Exploration of practical knowledge has not evaded allied health research. Mattingly and Fleming (2008) articulate a number of tacit and unexamined features of practice, and building on their earlier work argue, that tacit knowledge is developed in action, and immediately accessible through a process of reflection. I could relate to making use of this intuitive background knowledge in my own practice. The later part of the 20<sup>th</sup> century saw growing acceptance that knowledge creation is possible and connected to the practical activity that humans pursue (Gustavsson, 2004). By deliberately reflecting upon underlying elements of practice, and paying attention to how knowledge is used and created, practitioners are challenged to make tacit knowledge explicit, because professional practice with clinical reasoning as its core is knowing within the broader field of professional practice (Higgs, Fish and Rothwell (2008). Thus, the knowing and doing of practice are concurrent.

### **Researcher lens**

Revisiting the philosophical roots of practice knowledge urged me to consider the matter of epistemology and the subsequent methodology upon which to position the current research. Intuitive decisions made during my clinical career, particularly my role in the setting of the Postural Management Clinic, was aided by my experience of working with families and in special schools. Interpreting events portrayed to me by others, which often related to user difficulties, I recall challenging occasions when reflective thoughts engaged in self-dialogue, 'I wish I could be in the home or school to see what is really going on'. Gathering contextual data of this nature may aid further understanding of the intricately related phenomena of interest. The intention was not to ignore existing theory and knowledge, particularly with regard to physical discomfort. The scientific literature introduced in chapters two and three has made a number of relationships explicit, for example, the relationship between pressure distribution and physical discomfort. These are however criterial descriptions using dimensional language (Stake, 2010); experientially I saw comfort and discomfort as episodic, changing across time with an orientation to the experience of the child or young person. In the natural setting, I could describe practices, and focus on situational behaviour with and without equipment use, possibly giving some meaning to the behaviours. Spending time in the natural setting would also allow some focus on the perceptions and beliefs of those who themselves on a daily basis give meaning to the behavioural expressions of the children and young people.

It became obvious that it would be difficult for this research to be unbiased or value free. I had already become part of the process, with account already extending to conceptualization of self, openness, and reflexivity in the research process. I had a desire to give some 'voice' to the children or young people, with implications for enhancing comfort requirements, but without making value judgements or inducing change. I wanted to describe, interpret or explain what was happening. Professionals and caregivers might then use the findings to inform current practice.

Most of the perspectives offered reside not within the quantitative paradigm, closely linked to positivism, rather within the interpretive framework of qualitative research. It would be very difficult to depersonalize this research, or adopt a simplistic naivety to the issues. Some possible antecedents of comfort and discomfort first warrant illustration. The quantitative interpretation of knowledge would be less helpful in this situation because of its predetermined nature and hypotheses testing where the intent is to isolate clearly cause and effect. Qualitative physiotherapy research, on the other hand, can explore the complexities of rehabilitation practice, and broaden and deepen understanding of health and disability (Carpenter, 2004). A number of researchers argue that this is a legitimate mode of inquiry within the discipline of physiotherapy (Smith, Jull and Grimmer-Somers 2009; Jones *et al.*, 2006; Johnson and Waterfield, 2004; Carpenter, 2004; Richie, 1999). In this approach to inquiry, method is not dependent on the research process and the issue under study (Flick, 2009). The knowledge generated is shaped through interaction between those involved in the research process (Carpenter, 2004). It takes into account 'the role of the researcher, the person reading a textual passage' (Creswell, 2007, p.3). The individuals from whom qualitative data are gathered also play a more central role in the researcher's design decisions.

Increasingly used in health care research, a qualitative framework incorporates a wide range of philosophical perspectives, but one of the difficulties is that of definition. Not alone, Denzin and Lincoln, renowned authors of all previous versions of the Sage Handbook of Qualitative Research state in their most recent edition, 'separate and multiple uses and meanings of the methods of qualitative research make it difficult for scholars to agree on any essential definition of the field' (Denzin and Lincoln, 2011, p.6). Diverse perspectives with multiple uses and meanings exist, which Creswell, (2009, p.173) states all 'vie for centre stage in this unfolding model of inquiry.'

## **Strategy of inquiry: case study**

Beyond procedures common to all forms of qualitative research are specific strategies of inquiry, but from philosophical discussion, there should be clear links to methodology. In establishing case study as the appropriate research strategy, dilemmas had to be resolved. Exposure of personal values and beliefs and study purpose advanced my guiding framework toward theoretical underpinnings that placed emphasis on human everyday experience. Unfortunately, this purpose was not straightforward as the phenomenological insights highlighted present an epistemological challenge. The experiences of interest belong not to the adults who facilitate equipment use but to the children and young people who do not have verbal communicative capacity. A phenomenological inquiry in this case could only yield data from proxy reporters or those who facilitate equipment use. I would be unable to question the very secrets of the constitutive lived experience (Van Manen, 1997) of the children and young people in the main study.

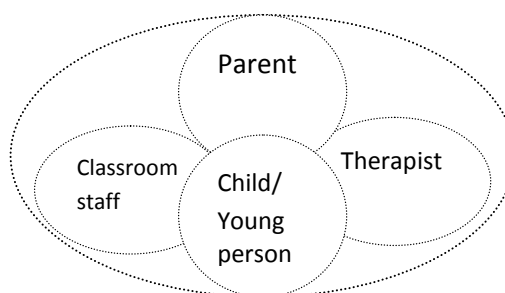
Ethnography as a methodology is 'a description and interpretation of a cultural or social group or system' (Creswell, 1988, p.58). It involves an ongoing attempt to 'place specific encounters, events, and understandings into a fuller, more meaningful context' (Tedlock, 2000, p.455). Both a process and a product, it incorporates 'views of the actors in the group (emic) and the researcher's interpretation of views about human social life in a social science perspective' (etic) (Creswell, 1988, p.60). This approach was appealing; such groups exist within the field of special education, but each child or young person also has their unique family group, outside of the school setting. A culture-sharing group could be a case, but 'the intent in ethnography is to determine how the culture works rather than to understand an issue or problem using a case as a specific illustration' (Creswell, 2007, p.73). The topic of comfort/discomfort is only one component of interest to a physiotherapist working with children with special needs. Being too inquisitive about other daily practices, with less focus on the topic of interest, could be a disadvantage within an ethnographic approach. The ethnographer locates key informants, individuals who provide useful insights. This would be a necessity in this study, as the children themselves are unable to use language. There would be involvement of the parents and school personnel; however, there was the desire to include the child or young person. The informants would be part of the social group but not the focus. Conventionally, ethnography utilizes core values of participation and immersion (Scott Jones and Watt, 2010). The intention was to undertake participant observation, but at the planning stage I held some personal doubts about the



acceptability of this in the family home, and of gaining access to achieve prolonged immersion in school environments. The child or young person's comfort or discomfort was to be the focus of this research.

Case study is sometimes referred to as a method (Hammersley and Gomm, 2000), often perceived to be interchangeable with fieldwork, ethnography, participant observation, exploratory research, and naturalistic inquiry. This is a reasonable observation as case research traces back to the Chicago School of Sociology, and casework in social work. In the 1980's, however, writers became more critical of the confusion that existed about case study. Bryman (1988) asserted that some writers treat 'qualitative research' and 'case study' as synonymous terms; those who advocated its distinction decidedly dissociated case study strategy from other forms of investigation (Robson, 2011; Creswell, 2007; Stake, 1995; Yin, 2003; Merriam, 1988). An argument emerged proposing case study design to be case orientated, but of a more flexible design, this being preferable when circumstances and research problems are appropriate. Stake (2003) argues that it is not a methodological choice but a choice of what to study, whatever the methods and this could be analytical or holistic; the case is the focus. Feagin, Orum and Sjoberg (1991) propose case study as an intensive, holistic description and analysis of a single entity or phenomenon. The approach aims to uncover the interaction of significant factors characteristic of the phenomenon, and is suitable for situations where it is impossible to separate the phenomenon's variables from their context. Creswell (1998, p.61) offers the definition of a case study as 'an exploration of a bounded system or case (or multiple cases) over time and place through detailed, in depth data collection involving multiple sources of information rich in context.' Constitution of the case is important, and this depends on the purpose of the study; I represent the identified bounded case for this research in Figure 5.1.

Figure: 5.1 The bounded case



The case is seen as unique as well as common, understanding one requires an understanding of other cases, but also an understanding of each one's uniqueness

(Stake, 1995). This gives scope for using multiple cases. Special features therefore define the bounded system of the case study; it is particularistic, descriptive, heuristic, and inductive (Merriam, 1988). Particularistic means that case studies focus on a particular situation, event or phenomenon; in this case comfort and discomfort in children using special/adaptive seating or other types of positioning equipment. Description means that the product of a case study is a rich thick description of the phenomenon under study. Other qualitative designs also emphasize rich description. The case study provides depth to the description. It is an analysis of events furnishing the dimensions of time and history to the study by providing information from a number of sources over a period of time (Feagin *et al.*, 1991). This is important because the presentation of some neurodisabilities changes over time. The researcher wants those informants to recollect past events that may relate to comfort and discomfort. Notwithstanding, there is also an interest in the present. This debate raises the following questions: is it possible to observe antecedents of comfort and discomfort? What are the beliefs and practices of others who are significant in the life of the child? Heuristic means that the case studies illuminate the readers understanding of the phenomenon under study. They can bring about new meaning, extend the reader's experience, or confirm existing knowledge. Perhaps those with most interest in this research are the significant others, who on a daily basis also make decisions on behalf of the child or children in their care. They make assumptions, but the experience of that action does not belong to them, it belongs to the child. Discovery of new relationships, concepts, and understanding, rather than verification or predetermined hypotheses characterizes the inductive nature of qualitative case studies (Merriam, 1988).

## **Conclusion**

Children and young people with developmental conditions that impair cognition or communication are unable to express their own views using language. A number of significant others, possibly all with different agendas, make decisions pertaining to need. The epistemological views outlined earlier commonly accompany an expectation that phenomena are intricately related; to gain some understanding requires exploration of human behaviour, interactions, relationships, and belief systems. Philosophical discussion and practitioner knowledge led me to consider case study as the strategy of inquiry. This research is value laden, but furthering knowledge of a perplexing topic is the purpose of rigorous research. Until the fieldwork begins the nature of the primary data remains obscure, but the flexible nature of the case study allows for multiple sources of evidence. The notion of a bounded system provided a

framework for focusing the design at the proposal stage, a prerequisite in the light of research governance and the NHS ethical requirements. In the next chapter, I focus on access, ethics, the methods used to generate data and the issue of quality, with data analysis a feature of chapter 7.

## CHAPTER 6

### METHODS

#### Overview of the chapter

Research design was the subject of discussion in the previous chapter. Underpinning assumptions led to the creation of a qualitative case study design framework. These foundations continue to form a thread in this chapter. At the forefront of method appraisal come the research questions; however the design itself became operational through the appropriate selection of methods to generate data for subsequent interpretation and illustration. The methods I use in the main study include interviews with significant others<sup>3</sup> within each case, observation and video recording in the classroom and day centre. For each method used to generate data in the main study, in this chapter, I intend to examine method supposition in conjunction with the contribution each method makes to the chosen methodological discussion. I will then explicitly describe and discuss the data collection methods I used. Finally, using personal reflexivity within each section, I will explore the methodological judgments I made during the course of the study.

In advance of data generation, two critical phases warrant addressing: access and ethics. I had to gain access and acceptance in order to implement the proposed methods but ethics warranted consideration prior to these. Given the nature of the study - involving children and young people with physical, learning and communication disabilities alongside significant others, as well as crossing health, education and social care boundaries - attention to ethical issues needed to be paramount. The aim of being reflexive originated in the preceding chapter. Here, the proposed methodology embodied respect for the children and young people as sensitive, dignified human beings. There was personal commitment to act virtuously. The methods direct me to unravelling a complex process in a naturalistic environment familiar to the child and supportive to the family, an environment that provides for the physical, emotional and psychological safety of the child and family. In this chapter, I focus on two issues relating to ethics. First, by returning to the philosophical explorations introduced in chapter five, I argue that research with vulnerable children can be ethical. Second, I detail the ethical principles followed, including the pursuit of ethics approval from the National Research Ethics Service (NRES) and other committees, and the processes

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<sup>3</sup> The term significant others is used when I collectively refer to parents, teachers, teacher assistants, key workers and therapists

used to obtain informed parental consent and child assent. The application of abstract rules, principles or guidelines cannot solve all ethical dilemmas. Doucet and Mauthner (2002) argue that being reflexive in an ongoing and evolving way should guide ethical thinking throughout the research process. The epistemological, ontological and theoretical assumptions outlined in chapter 5 thus, in turn, led to the reflexive self. If responses surface from the same sensitive and insightful awareness of what is salient in practice, this avoids what Van Hooft (2006) refers to as a prescriptive ethical paradigm. Discussion then develops around the methods used to generate data. The issue of quality becomes the topic of discussion in the last section of this chapter. Here, I formulate an overview of quality management, transparency and triangulation in the research process, beginning with a short methodological discussion.

### **Ethical research with children and young people with profound and severe physical, learning and communication difficulties**

Ethical research is the responsibility of the researcher and active engagement with sensitive dilemmas compelled me to think beyond the hurdle of regulatory frameworks and ethics committees to the reality of acting honourably in the field. In establishing purpose, I identified how the research would benefit current and future users of equipment as well as other participants in the research. I also had to consider the legalities of obtaining informed consent and assent, issues of child protection and ethical practicalities of method. Biomedicine has been at the forefront of establishing standards of good practice in respect of research ethics (Alderson and Morrow, 2011; Dominelli and Holloway, 2008). Following the 1964 Declaration of Helsinki specific guidelines became available for medical research involving children and then, in response to the 2007 Mental Capacity Act, those young adults who lack the capacity to consent (Medical Research Council Ethics Guide [MRCE] 2007, 2004; Alderson, 2004). Legal frameworks allude to duty, rights, harm, and benefit. All participants should be informed and have the right to choose to participate and withdraw. Their privacy and personal information must be treated confidentially, and only information used for which consent exists.

Involvement of children in research is not new. However, government legislation, largely influenced by the spirit of the United Nations Convention on the Rights of the Child (UNCRC) (1989) and subsequently implemented into UK law in the Children's Act (1989), advocates the need to involve children in research (Alderson and Morrow, 2011; Neill, 2005). This has resulted in increasing involvement of children as research participants, not subjects of research. The theme 'researching children's experience,

perspective and voice' is now common place and is a growing trend (Alderson and Morrow, 2011; Hill, 2005; Farrell, 2005; Graue and Walsh, 1998), although debate does exist about the extent of involvement (Greig, Taylor and Mackay, 2011). Anderson and Morrow (2004, p.11) admirably addressed the lack of attention to ethical issues within social research, stating that all researchers who aim to add knowledge evaluate services to inform and to change policy and practice, and to promote children's participation and inclusion must agree to observe high ethical standards.

With distribution of control rightly moving in the direction of research participants, Scott, Wishart and Bowyer (2006) and Farrell (2005) argue that such protective measures may limit opportunity for some groups to be involved because of their vulnerability. The children and young people in the main study have physical, learning and communication difficulties, lack the capacity to consent verbally, express their needs or defend their interests. In respect of ethics, they are vulnerable and prone to being easily manipulated (Charles-Edwards and Glasper, 2002; RCPCH Ethics Advisory Committee, 2000). They form a group who in the past have had their personhood denied (Hogg, 2007). For these children, young people and their families the list of functional, medical and educational problems that require addressing is often enormous and to omit research in a particular group prejudices that group (Farrell, 2005; Hill, 2005; Yan and Munir, 2004; McIntosh, 2002). Pain arises from many typical and uncommon sources in children and young people with disabilities (Oberlander and Symons, 2006); and freedom from pain and discomfort should be a basic human right. Research, which potentially advances everyday quality of care, is beneficial. The children and young people in the main case study may appear to be less active participants, but nonetheless, as illustrated in chapter 5, they are not viewed as 'unknowing objects' (Alderson, 2004). On the contrary, an argument, which has prevailed throughout this study, is that of their ownership of the comfort/discomfort experience. The experience belongs to the child or young person.

The repositioning of children as participants has been referred to as a paradigm shift (Christensen and James, 2008), which gives children status and recognition and remains central to respecting their worth as human beings. This theme runs alongside developments with regard to the inclusion of children and adults with learning disabilities in participatory research and involving them in consent procedures (Scott, Wishart and Bowyer, 2006; Gilbert, 2004; DoH, 2001a, 2001b). Insightful awareness is necessary in preference to making assumptions that people with learning difficulties do not have the capacity to make decisions about their lives; they lack cognitive sophistication but are aware subjects (Alderson, 2005).

### ***Ethical regulations***

In the UK high standards of ethical research practice are expected across all disciplines. This is addressed by a number of governance frameworks at institutional levels (BERA, 2011; DoH, 2005), and networks of research ethics committees convene to vet potential research projects. Formal procedures ensure researchers give due consideration to the nature of any ethical concerns. Ethical approval was obtained from the university Research Ethics Committee (REC), the National Research Ethics Service (NRES), the National Patient Safety Agency (NPSA) and an NHS Trust based R&D, and their guidelines have quasi-legal status (Alderson, 2005). In the respective applications for approval, standards of good practice and answers to questions about potential harm or benefit, honesty, fairness and respect for those involved were made transparent. It is in the area of rights and dignity that some of the most difficult issues relating to research with children arise (Allmark, 2002).

### ***Informed consent and assent***

Consent and assent are major themes. Individuals, including children, who take part in research, should do so knowingly before consent is forthcoming. It is expected that research participants understand what their involvement will entail. The age at which children are able to consent to medical treatment, medical research and social research continues to be the subject of considerable debate. Under the UK Children's Acts of 1989 and 2004, a child is defined as any person under the age of 18 years, and for purposes of medical research, as opposed to medical treatment, parental informed consent is necessary (MRCE, 2007, 2000). Nonetheless, the child should give ultimate affirmation to his or her participation in a study and guidance does emphasize respect for the refusal of young children and those with learning/intellectual difficulties. For this research parental permission and assent from the child or young person was vital.

### ***Child/ young person assent***

I had grappled with the philosophical debates about rights, harm and benefits, but nonetheless I was aware that I would not be able to obtain the assent of the children and young people in the same way as those participating in the focus group because of their profound learning and communication difficulties (please see chapter 4 for further discussion of this issue). To avoid the issues of exclusion for those individuals who are unable to give legally valid consent because of a profound learning difficulty a different approach was required (Kellett and Nind, 2001). Assent, for those unable to give valid consent, is not a legally endorsed process, although involvement of the child in the

process is recommended (Lambert and Glacken, 2011). It may be, as suggested by Dockett and Perry (2011), a relational process, whereby a child's actions and the adult responses taken together indicate assent to participate. In the current study, therefore, the children and young people's response to my presence in the research setting was important. Allmark (2002) states that if a child is unable to give consent through verbal means, their non-verbal behaviour may be suggestive of dissent and their right to withdraw from the study assumed. At the outset, I did not know the children and young people well enough to be able to make judgements about their communicative potential and capacity for understanding. I was made aware that some of the children and young people could not use symbols or reliably use low tech communication, such as a single switch BIGmack (2012) communication aid or Talking Mats (2012), which allow pictures to be attached and regrouped. I took the stance that if I obtained informed parental consent and also worked with the team who had a relationship with the child, this would help me evaluate and continuously re-evaluate the child or young person's willingness to be involved throughout the study. Such a partnership supports inclusiveness, whilst safeguarding the more vulnerable when uncertainty exists about the person having the capacity to understand the information provided. It also ensured that the children's rights were not violated. I made a point of always introducing and explaining myself to the children and young people and remained vigilant to their expressions and behaviours as part of the ongoing research process. Four of the participants did use some intentional gestures. One child in particular initiated interactions with me by passing toys whilst another smiled in response. The staff indicated that this pupil also sticks her tongue out when she is not happy or does not want to do something. Another reached out to take hold of my hand, in a similar manner to his interactions with staff, while the fourth appeared to use the same gestures with me as with familiar staff. These gestures were taken as assent. Dissent was not something I encountered, but I recognized that this was a subjective view based on intuition and analysis of the expressions recorded on the video when I was in close proximity to the children and young people.

### ***Parental informed consent for child 'case' participation, and parental informed consent***

In order to comply with the recommended procedures for obtaining informed consent (National Research Ethics Service (NRES), 2007; Central Office Research Ethics Committee [COREC], 2000) the parents and their children were formally invited to participate (Appendix 8). However, for consent to be valid they needed to be



appropriately informed. Initial contact with each family was through an NHS intermediary, as identified in the research proposal. I then sent an introductory letter to those parents who had expressed interest in the study, suggesting a home visit to explain the study and informed consent procedures in more detail. Initially all families contacted indicated a willingness to let me visit them at home where adequate time was allowed to give information and, for the family, the opportunity to ask questions. This was time consuming but perceived as an important and necessary component of the research. After all, I was asking parents for two sets of permissions, first, for his or her child to be included in the research, and then for their own agreement to participate. I did not place parents under any pressure to take part, assuring them that their decision would not affect their child's care in any way. I also assured them of personal and organizational confidentiality throughout and that they could withdraw at any time. Information sheets and signed consent forms constitute documentation of a formal agreement made between the researcher and the participant. The advantage of a home visit to discuss the study and consent was that it enabled me to explain the research and then respond to questions. This process also allowed for explanation of the ethical governance procedures and the status of my CRB clearance, a prerequisite for any work with children. At the end of the meeting, the family received a copy of the information sheets and consent forms (Appendix 8). Participation must be voluntary. No immediate consent was expected, as the family would need to make the decision about whether the question posed was important. I reminded participants they were under no obligation to sign the consent form at this stage and advised them to consult the written information. Some families indicated their willingness to sign the form immediately, stating that they might forget to return it otherwise. Both parents were present for five of the sixteen initial meetings.

All participant information sheets, letters and consent forms were subject to ethical scrutiny by the SEC, LREC and R&D. Informed consent is, however, not a one off event (Goodwin, 2006); rather, its achievement demands continuous negotiation of the terms of agreement as the study evolves. This was necessary as the nature of collecting varied data from different individuals and in a range of settings was logistically challenging due to school holidays, special weekly events and staff sickness.

### ***Therapist, teacher and teaching assistant consent***

The significant others identified within each case and accessed through gatekeepers were also participants and therefore retained their individual rights in respect of

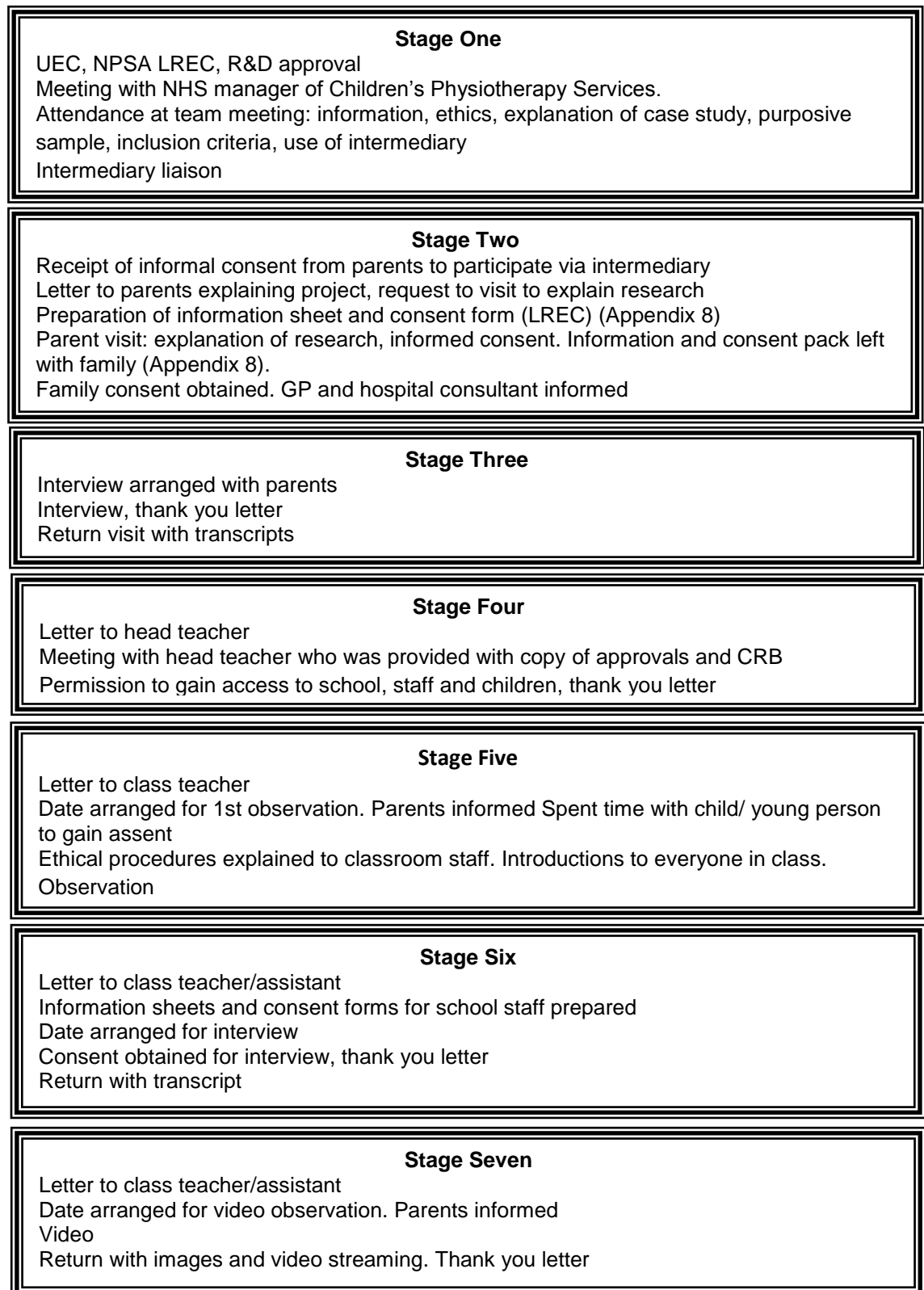
informed consent. A point of note, in the school setting, is that a teacher is in *loco parentis*, but does not have parental responsibility. They can grant researchers access to the children but not consent to the research. Access to school staff was essential. The flow diagram in Figure 6.1 documents this procedure within the process; a copy of the informed consent pack can be found in Appendix 9. A copy of the informed consent forms, previously ethically scrutinised by the SEC, LREC, and R&D, was given, to the head teachers of each school, together with the researcher's CRB clearance, as testimony to the codes of ethical conduct I intended to follow during my research on school premises. Being under no pressure to take part and assured of personal and organizational confidentiality throughout, all the significant others gave informed consent.

### ***Anonymity and confidentiality***

Anonymity and confidentiality, alongside consent, are other hallmarks of ethical research (Cuskelly, 2005). It is a requirement of all research that participants receive assurance that there will be no dissemination of names or distinguishing identities in any written or verbal form. I articulated this to respondents both verbally and within the written format of the informed consent package.

I was troubled by some events regarding ethical considerations and these warrant reflection here. All initial negotiations took place through an intermediary and this smoothed progress of the introductory meeting with families who had provisionally agreed to take part. The focus was to be an explanation of the planned research and issues of informed consent. However, despite attempts to steer the discussion towards the purpose of the meeting, family members understandably preferred to talk about their experiences in dealing with their child's disability. Was the evident transparency in approach due to my professional status as a physiotherapist or because I was a researcher? Some parents raised issues of service provision and others talked about the equipment used by their child. All this would have been valuable information had the families already agreed to take part in the study. However, I did not abuse my position of trust and waited for signed documentation before commencing data collection. Permission to conduct the research went beyond consent forms. In the educational setting the head teachers and some classroom teachers had pivotal gatekeeper roles, yet remained on the outside of the two-way existing agreement between the researcher and participants. On one occasion, I sought access but misjudged a gatekeeper's understanding and interpretation of ethical codes of practice.

Figure 6.1 Access Negotiation



This became apparent when I received a telephone call from a professional external to the school seeking advice about one of the children in the study. This constituted a third-party breach of privacy. It was a delicate situation, which was resolved through discussion and explanation. However, this incident helped me further conceptualize ethics within school-based research and the care needed to maintain privacy and confidentiality in a public setting.

## **Access and Sample**

Sampling in qualitative research often follows a different logic from quantitative research, which pursues generalization; however, its importance in managing the quality of an overall research design cannot be underestimated. Flick (2007) highlights the critical importance of access. This, he argues, determines how far the plan of research formulated in a design is going to work in concrete research practice.

Qualitative researchers work with small samples of people, who are 'nested in their context' and studied in depth', often sampling purposively (Miles and Huberman, 1994, p.27). Creswell (2007, p.125) describes this as 'the strategic selection of individuals and sites for study because they can purposefully inform an understanding of the research problem'. Nonetheless, reasoned decision making is necessary in the selection of sites, people, events and materials. This inquiry called for different levels of sampling. Sampling took place as part of the preliminary study. For this and the main study I also had to sample schools. Then there were decisions to be made with regard to persons constituting the 'case'. For observations, I sampled the situation and for video, I sampled the event. Further sampling of materials took place during the analysis.

### ***Selection of the site for 'case' sampling***

Developing contacts in the field is an important part of preparation for gaining access. Feldman, Bell and Berger (2003) view access as a process of building relationships, making such a process less formidable. Through a network of influential key contacts, supported by subsequent NHS LREC approval, I gained permission to access the children, 'deemed NHS patients', and their families, within the geographic location of one sub-regional NHS Trust. Insider practitioner knowledge had previously guided me toward thinking about 'the special school' as a site to access cases and this now provided an indirect opportunity to seek access to special schools within one geographic location.

Inclusiveness within the education system exists and many children with disabilities are now educated within mainstream schools (DfES, 2004). Nonetheless, prior experience of working within special education led me to believe children that with PMLD would be continuing to receive their education and have their health needs addressed in the locality of a special school. Multiplicity of difference was one of the factors which focussed my research design; I was looking for relevance of cases, not representativeness. I was not looking for a 'typical case' or 'extreme case'; insider knowledge had led me to believe that within one education authority special school I would get maximum variation. This left the field open for theoretical sampling at a later point. Stake (1995, p.4) states that sometimes a 'typical' case works well but often an unusual case helps illustrate matters often overlooked in typical cases. Creswell (2008, p.129) further supports the notion of 'maximum variation in a sampling strategy to represent diverse cases'. These viewpoints combined with my knowledge of diversity within special education increased the likelihood of obtaining the small sample from one geographic area (Male and Rayner, 2007). The selection was, therefore, restricted to the boundaries imposed by one LREC and made accessible through an NHS employee gatekeeper.

The process of narrowing the field to one area warrants explanation. Miles and Huberman (1994) refer to geographical selection as a sample of convenience, a type of sampling strategy that saves time and money but often at the expense of information and credibility. Perhaps, if generalisation was the intent, this argument is valid. At an early stage in the design, the option of accessing cases through the Regional CP registers was a possibility. This would have necessitated an extra tier with regard to access; however, there could be no guarantee that the 'cases' I was seeking would be identifiable from the available data. In addition, ethical approval would have to be sought from a central, as opposed to a LREC. Even before the stage of case sampling, the networking required in tracking down gatekeepers and gaining access to schools, within a combination of local education authorities across the region, would have had massive implications with regard to time and resources. I used insider knowledge of the special school system within the region to locate suitable sites as a source of access to cases. Professional networking gave several options, and awareness that help would be available when it came to selecting cases. However, as the research had a health care remit, the final decision with regard to narrowing down the geographic area would be determined by NHS ethics committee approval. Rarely is access gained without going out and meeting people (Feldman, Bell and Berger, 2003), and it was endorsement at two such meetings, one with a representative from the R&D research

arm of the organisation and the second with a physiotherapy service manager, which proved decisive. The opportunity had arisen for me to submit the proposal to their NHS Trust. A successful application would enable access to the NHS staff working into special schools then, through them, access to the families, children and young people and, potentially, the schools.

### ***Selecting the child for the 'case'***

From the schools selected, one primary and the other secondary, there were subsequent choices to make about the central figure within the case - 'the child or young person'. The primary decisive factor was the opportunity to learn from the children and young people who use adaptive equipment, so all those selected had to be users, in addition to having a learning and communication difficulty.

I had initially envisaged the children as having a diagnostic category of CP as research would appear to suggest the population of children with CP are the main users of adaptive seating (Lachmann, Greenfield and Wrench, 1993). However, as the causative factors leading to CP are more clearly identified, and a range of other conditions have similarly acquired movement difficulties, it appeared inappropriate to restrict the study to those with a label of CP; after all, it was the child and their experience which was to be the focus.

Stake (2003) states that the unique aspect of case study is the selection of cases to study and that the case or cases of choice should be those which offer the greatest scope for learning. In the event, sampling was nearly inseparable from conceptualisation of the research design as the notion of the 'case' arose based on relevance to the research questions and the theoretically informed design. The case, as presented, evolved, with its own unique pre-designed 'case' framework. Each 'case' within the enquiry was to be substantive with individuals sited within an identified case boundary. Collective cases then allow for maximum variation, representation of diverse cases and multiple perspectives (Creswell, 2007).

Sampling decisions cannot be taken in isolation (Flick, 2006), and two determinants were influential. I was not in employment by the local NHS Trust or the local education authority (LEA), and whilst I subsequently received an honorary contract, the entire initial liaison was through intermediaries. This customary practice was acceptable as NHS and LEA have duties under the 1998 Data Protection Act to ensure personal and sensitive data processing is for clearly defined and necessary purposes only. The

manager of Children and Learning Disability Physiotherapy Services gave permission for me to attend a team meeting for the purpose of introducing and talking about the sample I wished to recruit. This meeting was successful, and with the manager's agreement, arrangements were put in place to contact the parents, initially, through an intermediary NHS member of staff.

The second major determinant I perceived in the final selection was the issue of ethics. This was a necessity for all participants, as, without parental agreement and informed consent, there would be no case. The original proposal and application for ethical approval stated eight to ten cases. Eleven families agreed to an initial introductory meeting and subsequently eight gave informed consent. One family declined because of their son's hospital admission whilst another family were already involved in a research project. The consent forms were not retrieved from the third family.

A dilemma arose because of this sampling process. The intermediary had obtained permission from the family of one child who fulfilled all the criteria with regard to using adaptive equipment but could ambulate with assistance. Encouraged by the views of Stake (2005), I made the decision to include this case because of its potential contribution to understanding the phenomena of interest. Stake states that each case is unique as well as common and that understanding one requires an understanding of other cases.

From the beginning, sampling was purposeful, which gives flexibility and opportunity to return later to sampling as part of the iterative process (Robson, 2002). A further selection of four additional cases took place toward the end of the study. These comprised two children in transition to the special school, and two young people in transition to adult services. This inclusion represented an opportunity to confirm or disconfirm contextual conditions as influencing the phenomena.

### ***Selection of 'significant others' within the case***

With the composition of cases established and parental agreement on behalf of the child obtained, I addressed the invitation for parents to participate. The initial and subsequent letters were, where applicable, addressed to both parents. Informed written consent from one parent I accepted as agreement for their child to participate and agreement for either or both parents to become respondents within the case. Both parents were present in five of the case interviews. I also involved the parents in the identification of suitable informants within the school setting. Miles and Huberman

(1994) refer to this as snowball sampling. I was searching for an informant, within the school setting, who had a 'special relationship' with the child or young person identified. This person, alongside the parent and therapist, would become 'nested' within the case (Miles and Huberman, 1994, p.28). The educational informants were identified once the relationships in the classroom became established. This only became possible with parental permission, access to the school, then eventually with access, via the head teacher, to the classroom. Information letters were, in the first instance, always forwarded to the classroom teacher as I also sought their permission to undertake the desired period of observation and recording of video images of the child using equipment within the classroom.

In summary, research can only come to fruition if appropriate processes are in place to guide and enable access to the sample. The special schools offered an advantage over mainstream schools due to the likelihood of children with physical, learning and communication difficulties attending and using adaptive equipment. In this regard, sampling was strategic and individuals and sites selected purposefully in order to inform an understanding of the research problem.

## **Methods used to gather data**

### ***How the individual interviews contribute to the exploration of comfort and discomfort***

The interview is a time-honoured process for gathering information, and the decision to include this method was almost instinctive; after all, I had engaged in purposeful interviewing regularly as part of my professional clinical practice. Yet here, the situation and underpinning purpose was different. Within a qualitative case study design I sought ways to help me explore the comfort and discomfort experiences of the children and young people who could not communicate using language or speech. They would remain the central focus of the research, yet I felt the significant others could further my understanding if I posed questions and listened to their views and opinions. The qualitative research interview fits this purpose. It allows entry into 'the other person's perspective' (Patton, 2002, p.341), which is viewed 'as meaningful, knowable, and able to be made explicit'. Rubin and Rubin (2005, p.35) argue that depth of understanding is a desirable feature of qualitative interviewing, requiring the researcher to follow up interpretations with more questions about what he or she initially heard. The words of Kvale (2007, p1), 'an inter-view where knowledge is constructed in the inter-action between the interviewer and the interviewee', further inspired me to reflect upon the conceptions of knowledge that I held and could bring to the interview.



Unstructured, open ended, semi-structured, focus group, telephone and on-line interviews are all described in the literature but I chose to be guided by Patton (2002), and Kvale (2007) as my research questions included factual and conceptual components and my participants would differ depending on their role within the case. Also I brought personal knowledge and skill to such encounters. In the main study, I had chosen to observe the children's non-verbal behaviours and interactions within the environment, but could not observe everything. Nor could I, in such a short period, gain the expertise of a parent or significant other who interprets a child's behavioural clues on a daily basis. Observation alone would not provide information about the postural management decisions made by parents and significant others. The interview had the potential to enrich other data sources, providing the participants did not feel threatened, or the need to justify anything. The methodological framework guided me toward the semi-structured interview.

### ***The interviews conducted and process***

Table 6.1 Interviews conducted

Parent or parents
Teacher or classroom support assistant or key worker (day centre)
Therapist
Focus group interview (chapter 4)
Adaptive equipment users able to communicate verbally (chapter 4)

I pre-arranged the interviews (Table 6.1) and used an interview schedule, prepared for submission with the research proposal documentation. This stopped the interview becoming too flexible by ensuring inclusion of particular issues at some point (Appendix 10). The individual interviews had similar structures, though each varied depending on its role within the case. The intention of this process was to enable the significant others to express their feelings regarding equipment use, describe the background context of their experiences, as well as their perceptions of comfort and discomfort as experienced by particular children and young people.

All of the parent interviews took place in the home setting, at a time convenient to them. The teachers' and teaching assistants' interviews took place in the school setting. Key workers were interviewed in the day centre, whilst interview locations for the therapists varied, held either in the school setting, or on NHS premises. The interviews were usually held in a quiet place, often the vacated classroom, whilst the children were in assembly. On occasion, the quietness was disturbed, for example due to frequent health and safety requests through the school intercom. I commenced each

interview with an introduction and reminder about the study's purpose. The importance of confidentiality was discussed, and I explained what would happen to the data and findings at the end of the study. With permission, the interviews were audio recorded. All except one participant agreed to the audio recording of their interview; in this case, I made hand-written notes.

The interviews ranged from 30 minutes to two hours' duration. The format was flexible, offering the possibility of modifying the line of enquiry. Probes and follow up questions, as described by Patton (2002), allowed me to go deeper into the interview responses, thereby enriching the data. Alteration of the topic sequence allowed flow of the respondent's narrative so that the type of data gathered was not limited in any way. The interviews with teachers and teaching assistants were shorter and more difficult to arrange because of the school curriculum. The professional interviews required fewer prompts whilst the longest interviews took place with the parents. At the end of each interview I asked the significant others to complete a checklist of behaviours which I had extracted from the Non-Communicating Children's Pain Checklist (Breau *et al.*, 2002) and the Paediatric Pain Profile (PPP) (Hunt *et al.*, 2004) (Appendix, 11). The letter of appreciation sent after each interview included reference to a further visit to talk through the findings. A verbatim, word-processed transcript was made of each interview and analysis began immediately on the first case in order to generate initial codes and categories.

### **Observation**

Observation is also a time-honoured process for gathering information within a qualitative framework. One of the assumptions I made at the research proposal stage, which ruled out a purely ethnographic approach, was the unlikelihood of being able to spend lengthy periods of time in the field. Ethnography was therefore set aside as an overall research design and observation became a data gathering method. The advantage of observation is that it provided me with opportunities to watch, listen, talk and reflect upon events taking place in natural settings where the children and young people spent their days. In line with Marshall and Rossman (2006, p.100) who quote Glesne (1999), there was opportunity to 'make the strange familiar and the familiar strange'.

With dates prearranged I always arrived early. This gave me time to speak with the classroom or day centre staff before the children and young people arrived. I discussed the purpose of the project with the staff and responded to any questions. I spoke about the importance of privacy and confidentiality, both with regard to the child and the

school. I explained that no observations would take place during personal hygiene tasks and reinforced aspirations of not disrupting routine class or day activities. I also asked if the staff could let me know if they wanted me to participate or join-in routine activities, and also if I was interrupting an activity or event because of my positioning within the room. As the other children and young people started arriving I made every effort to be friendly. Those who communicated verbally and were mobile acknowledged my presence, coming over to ask my name. If I positioned myself in the book corner the children would lift a book out of the box, give it to me and ask me to read. Children's photographs, and names, were displayed on the classroom walls and this helped me relate to the other children. Whilst waiting for the study child to arrive, I would make notes about the layout of the classroom, adaptive equipment already in the room and details about staff-pupil ratio.

I observed each study child and young person for a full day. The observations took place on a separate occasion from the video recording which also took place in the classroom or day centre. My observations commenced immediately upon the study child's arrival at school or the day centre. I considered this to be important as some individuals had spent at least 45-60 minutes in transit from their home. The observation continued until the end of the day. I stayed with the child for all curriculum and non-curriculum activities, except personal hygiene which I deemed an invasion of privacy. I observed the child at lunch and weather permitting spent morning and lunchtime break outside with the children. At the beginning of each school day there was a period of pupil-selected activity until all the children in the class arrived. Children with independent mobility removed their own outdoor clothing, and this allowed staff time to read the school/ home daily journals or assist other children to remove their coats.

I had gained access to the classrooms, but the nurturing of trust and credibility was something I envisaged taking longer. In preparation, I developed two observation grids for recording events (Appendix 12) in anticipation of questions from staff about my observations in the classroom, particularly in the early stages of fieldwork. I felt these would help explanation. However, a number of events served to widen the field under study. My observations at first focused on the child and I documented facial expressions, vocalizations, limb movements, trunk movements and postural adjustments. However, I soon found, that, in the observation period, the field note taking greatly outweighed the grid work, which I had intended to complete every 15 minutes. This was due to events within the environment and if I had restricted documentation to the observational grid there would be no record of these salient contextual influences.

One of the most difficult dilemmas for me in this setting was taking on the role of the researcher. Although I was never employed as a physiotherapist within this geographic area, I had worked in similar settings and had insight into the culture. I had the skills to be a physiotherapist, an assistant and a voluntary worker but now my position was that of observer researcher, and I had to take on this role.

### **Video observation in the naturalistic setting**

Video recording allows for repeat observation of events. I considered the postural positions adopted by the children and young people, their non-verbal behavioural expressions and the equipment used to be the main focus of the recordings. The possibility of micro level analysis attributable to video recording was one of the features that attracted me to this method. It is a means of addressing implicit interests articulated within the research questions: non-verbal interactions and behaviours. At the proposal stage, there was interest in the reliability and consistency of judgments with regard to interpretation of facial expressions by proxy reporters. Scherer and Ekman (1982) provide an extensive overview of the approaches to the measurement and analysis of non-verbal behaviour, which traditional qualitative researchers may perceive as grounded in a theoretical perspective closely allied with empiricism (Prosser 1998). As argued in chapter 5, this is not in keeping with my person-centred worldview. Nonetheless as a physiotherapist I recognized the usefulness of this tool in the analysis of human movement.

The words of Flick (2006, p.221) hold: 'participant observations are confronted with the problem of the observer's limited observational perspective, as not all aspects of a situation can be grasped'. As explained, a number of events served to widen the field under study but there was also the requirement to stay focused on the research questions. I described how difficult it was to accurately record transitory facial expressions and close attention to these reduced the quality of other observations. As I moved into the analysis stage video became an invaluable tool and I began to realize the importance of the contextual interactions on the facial expressions and body movements. These had failed to gain my attention in the early days of child case focused observation. Video-recorded vignettes are comparatively common in research where participants comment on recorded observations (Hughes and Huby, 2002). Yet these may be devoid of context. I sequentially combined observation and video, so that when it came to the analysis I had already gained some familiarity with the child or young person. The video recordings took place on a different day from the classroom observation, as I wanted to become familiar first with the classroom and day centre

settings. I took selected, recordings of everyday events and happenings in the classroom both close ups, and panoramic views. What I filmed at a specific moment was based on two factors - ethics and the research questions.

The children and young people in the main study were included in class and community activities with others who also have learning difficulties. Many of these pupils were independently mobile and there was the likelihood that they would be distracted by my presence. I therefore made every effort to blend in with the children whenever possible. I did not disrupt teacher-led group activities, where the teacher was facilitating the whole group. Occasionally I was able to take side views of the child or young person during whole group activities, for example, circle time. In order to limit the technical presence of the camera, the recording was not continuous, but limited to events perceived to add rigour to observational interpretations. These were primarily a combination of non-event and event related behavioural changes.

I minimized the technical presence of the recording device by using a small, portable Sony, digital hand held recording camcorder. This records image and sound data onto 8cm DVD-RW discs, enabling close-up and distant shots. These discs allow recording of movie and still images, playback on a DVD player once finalized, and transfer of the recorded scenes to a computer for editing. A fully charged battery pack allows 80-90 minutes' continuous recording time, with 30-40 minutes being the typical recording length (Sony Corporation, 2005). Two batteries were available as the charging of the battery takes 130 minutes. Camcorder operation, for example, switching the camcorder on and off, which was a frequent occurrence, affected the availability of recording time. The images were stored on the disc in a VIDEO-TS folder in JPEG format, then converted to MPEG format for playback, and finally uploaded from the DVD drive into ULead Videostudio 10 package.

In respect of methodological argument, the use of video in research was a major ethical consideration. Informed consent was in place but once in the field a number of factors intertwined with ethics to govern the 'filming'. These were self-imposed restrictions, not issues raised by the gatekeepers. For educational purposes, the schools have parental consent to take video, but there are exceptions where a parent does not give consent. With this in mind, I did not take any recordings in the more public places within the school or day centre, for example, whole school assembly. I also did not video personal hygiene, and refrained from recording an event if the child became medically unwell.

In the research proposal I stated that I would only video each participating child, but that if other children suddenly crossed the recording area I would edit that out. In gaining access to the schools and then to the individual classes within school, also proposed that I would not cause disruption to the events of the school day. However, the act of 'shooting' makes the researcher more visible. Prosser (1998) refers to this as procedural reactivity and claims that this is one of the limitations of video recording to collect research data as it may potentially influence the participant's rapport and inhibit everyday behaviour and activities. When making arrangements to visit a choice of dates was always offered and I asked staff not to change any planned activities because of my visit. In the event, I had no control over this. The biggest threat I perceived was staff changing their behaviours due to my presence or the presence of the video camera, but on reflection, I did not consider this an issue as for long periods the camera was ready to shoot, but not recording. I may have been invisible most of the time to the child or young person who was the 'case', but I do not think I ever became truly invisible within the classroom. Most of the other children in the classroom were independently mobile and did know I was there.

Another frequently articulated limitation of using a video camera to collect research data is the time it takes to review and interpret the data. Analyses aside, it takes the same length of time to view the video as the actual video recording time. In addition a non-image based format has to be used to record interpretations. In summary, once the process commenced any preconceived ethical concerns I may have had proved groundless as children are familiar with the use of such equipment in the classroom.

### **How can these methods contribute to the development of greater confidence in the research?**

For qualitative research, the focus of quality has, in the 21<sup>st</sup> century, shifted from fundamental epistemological and philosophical levels to more concrete and practical levels, with Flick (2007) arguing that the consequence of diversification and proliferation in the range of approaches has made it difficult to develop universal quality criteria. Often referred to as evaluation criteria, the terms reliability and validity, have been subject to criticism. Some scholars propose criteria that are parallel or equivalent to those accepted for quantitative research, replacing the criteria of internal validity, external validity, reliability and objectivity with the parallel criteria of credibility, transferability, dependability and confirmability (Flick, 2007). Irrespective of terms, rigour is what matters (Carpenter and Suto, 2008). Ensuring trustworthiness in this qualitative inquiry remains grounded in my efforts to establish confidence in the integrity of the data, analysis and interpretive findings. I have not set out to generalize

the findings to populations but do want data which explores previously assumed premises, to be contextually rich so that theoretical gains in understanding or new interpretations become possible. The findings can then act as exemplars for others who can determine relevance to their particular situation (Zynanski *et al.*, 1992).

I have made the paradigm assumptions, which partially govern the choice of validity procedures, explicit while the strategies for promoting quality within this framework, to this point remain implicit. In establishing the research, I disclosed personal beliefs and assumptions and it is the ontology identified in chapter 5 that continues to be the lens that I use to determine the credibility of the study.

The value of case study research is its uniqueness. Validity is about the credibility of the descriptions and explanations offered. As qualitative case study does not lend itself to establishing cause and effect, internal validity is not an issue. However, construct validity, where the study illustrates what the researcher claims, is an issue, the closest threat being myself. Therefore, from the outset, I had to establish an audit trail to document decisions and activities and use 'reflexive accounting' (Altheide and Johnson 1994 cited in Creswell and Miller, 2000) to describe biases evolving from personal experience, ethical, methodological decisions and analytical assumptions. I explain triangulation, (the procedure where researchers use multiple and different sources of information), in more detail in chapter 6, because triangulation is at the core of case study design. I could not aim for validation of the findings from the children and young people in the main study; however, I would be able to achieve some consensus from the other participants by feeding back a resume of what they said in the case interview (Flick, 2007), referring back to the main statements in the interview. This was similar for professional interviews, but on occasion, due to unavoidable events, transcripts only were returned for comment. Nonetheless, member consensus of interviews was not the only way of validating the data. I sought to validate the video case findings by taking video streams back to the teachers and therapists. To minimize the time taken to do this for the participants, I adapted a version of the comfort questionnaire (Kolcaba, 2003) (Appendix 13), which is usually completed by a person experiencing comfort/discomfort. Participants observed the previously recorded video clips or still images and then made judgments about the child or young person's behavioural expressions and comfort/discomfort status.

## **Conclusion**

The ethical implications of this study constitute an essential consideration and I gave appropriate thought to potential ethical dilemmas long before data gathering commenced. Permission to conduct research goes far beyond the consent forms. Effective negotiation involves respect, which in this study involved commitment to on-going renegotiation of access. This access brought responsibilities. The parents welcomed me into their homes, the therapists saw me as a peer, the schools granted access and teachers opened their classrooms to me. Greig, Taylor and Mackay (2007, p.176) quote the words of Lawrence Stenhouse, 'research is systematic enquiry made public'. The dissemination of the research with emphasis on case study description will be an ethical challenge. Some writing which illustrates relations among individuals or observed cultural practices will be inevitable. The challenge will be to accept identity as a researcher, report with honesty and give careful attention to the preservation of anonymity and confidentiality. Under the framework employed for this study, data gathering and analysis proceeded simultaneously. In the analysis, I aim to increase contextual understanding of comfort and discomfort by describing and interpreting the data gathered, a process discussed in the next chapter.



## **CHAPTER 7**

### **THE APPROACHES USED IN THE CONTEXTUALISED ANALYSIS OF COMFORT AND DISCOMFORT**

#### **Overview of the chapter**

The intent of this study was to achieve a deeper understanding or explanation about the comfort needs of children and young people who use adaptive seating and other items of positioning equipment. To achieve this, I adopted a methodological approach that allowed development pertaining to the contextual focus of the research and the more open nature of research questions. The processes leading to data accumulation received due attention in chapter 6 of this thesis. Sense had to be made of these data so I turn discussion in this chapter to the process of analysis and the notion of trustworthiness, as others will determine whether the knowledge assembled from this process is valid and distinct from personal opinion. The audit trail offered in this chapter, alongside supporting appendices, documents the analytical processes which give content to subsequent chapters in this thesis.

The chapter begins with a discussion of the analytical strategy, and then I outline the modes of representation and sub-processes involved in the management and retrieval of data for each of the separate data sets. As different levels of data sources and methods produced data for the analysis, triangulation warrants discussion. I follow this with a section that explains how the data were organised and displayed. Then to move the analysis forward I describe how the non-cross sectional coded data, and then cross sectional data, were organised into meaningful groups. Finally, I focus on the broader level of thematic development, which I use to produce and structure the report of actual findings.

#### **Rationale for analytical strategy**

Gibson and Brown (2009, p.6) provide a critical summary of approaches to the analysis of qualitative data and begin with a simple definition, 'using data to deal with some problem, issue or 'other'. Analysis they argue is contextualised, about the relationship between 'data' and 'problem', and viewed this way, 'data' and 'analysis' become 'much less abstract, and more tightly integrated into the research process as a whole'. This was helpful to me as it reinforced the inductive nature of qualitative research, and the painstaking process of making a decision in regard of case study design. The analysis had to be congruent with method and this meant preservation of the uniqueness of

each case through documentation and full analysis, a view supported by case study advocate Robert Stake. Stake (1995, p.74) attaches meaning to small collections of impression without consciously feeling the need for data aggregation; he speaks of 'direct interpretation of the individual instance' and 'aggregation of instances' as important analytical strategies. The qualitative researcher he states 'concentrates on the instance, trying to pull it apart and put it back together again more meaningfully - analysis and synthesis in direct interpretation'. Mason (2002) likewise supports case study data organisation in studies where context has enormous impact, and a need exists to gain a sense of distinctiveness of the elements of the data. Even authors with great affinity to cross sectional data analysis often begin with case analysis (Miles and Huberman, 1994). A specific, early challenge reinforced the importance of this congruence between method and appropriateness of data analysis techniques, and the iterative approach at work to keep interpretation contextualized. The second case study, whilst fulfilling sampling requirements in terms of equipment use, appeared counterintuitive to the frequently documented decision making in regard of postural management. The child had some postural control, but did not possess the important adaptive skills to cope safely with this in all environments. This pressed me to retain a focus on the case, thus avoiding too early a move onto cross case analysis of the collective cases.

To achieve what Mason (2002, p.165) describes as 'contextual, case study and holistic data organisation', I produce an explanation of the processes that characterise the analysis of each case before moving onto to any cross case comparison. Creswell (2009) and Grbich (2007) claim that some common analytic practices within particular contemporary qualitative approaches are flexible entities, which can be lifted out and adapted to suit specific need. The procedure I followed requires acknowledgement of these borrowed practices, including the use of the paradigm tool described by Strauss and Corbin (1998) to assist in development of a thematic analysis. Although I do not subscribe in this study to the full theoretical commitments of a grounded theory approach, I take heed from authors who suggest that certain methods of data analysis used in grounded theory can be transferable, and used consistently by other approaches at certain phases of analysis (Holloway and Todres, 2003). A discussion of these tools is found at appropriate points in this chapter, but before moving on it is important to demarcate an understanding of the expression 'thematic analysis', often viewed by some as an analytical tool (Ryan and Bernard, 2000) and by others as a specific, but flexible approach in its own right (Braun and Clarke, 2006). An approach that involves searching across a data set to find patterns of meaning, thematic analysis

is unlike other analytical methods, as it is not theoretically bound. It can be a method 'that works both to reflect reality and to unpick or unravel the surface of reality' (Braun and Clarke, 2006 p.81). Bearing in mind the theoretical assumptions of this study documented in chapter 5, this approach offers a distinct advantage, as I do not deny my role in the identification of themes and patterns.

### **Modes of representation: transcripts of audio and video data**

Low-inference descriptors begin the process of providing evidence in support of a data audit trail, examples of which are scattered throughout the following two chapters in the form of data extracts. These make a contribution towards helping to satisfy the criterion of procedural reliability (Silverman, 2006). This was achieved by recording all face-to-face interviews, except one, using a mini disc recorder, then carefully transcribing these into a new representational form (Gibson and Brown, 2009), that of text, in preparation for later reduction, extraction and discussion. I made abridged hand-written notes for the single interview not audio recorded. Similarly, I produced transcripts of the video recordings. The mini disc recorder and the video replay facility allowed me to review the context.

The text transcriptions of the interview data provide a verbatim, concrete account of what the significant others actually said. I made no decisions at this stage about which features of the data might be relevant. The transcripts included all questions, which provoked answers, and probes that prompted expansion of response. A transcript is a more accurate representation of what a person says, rather than the researcher's reconstruction of the general sense of what the person said. In the one interview I was unable to record, I had to rely on memory for the transcription because brief notes were made as I found myself having to interact with an infant sibling who was also present.

Textual transcription of representation modes attempt to mirror the data, its character and meaning (Gibson and Brown, 2009). This was enhanced by attentive repeat listening and viewing. Transcriptions of video files are a re-presentation of events. Ethnographic content analysis was the approach used to describe the content and context of each MPEG video file, in preparation for future association with other data sources or direct interpretation (Grbich, 2007).

## **Data management: the contribution of coding**

Coding is an allocation and labelling process that compels 'the researcher to make judgments about contiguous units of text' (Ryan and Bernard, 2000, p.780). I had transcribed textual material to analyse and therefore made the decision to use this strategy, which consisted of a number of sub-processes. I documented the coding process to make this explicit which was an issue of importance as my status meant I had to be open to false claims based on personal subjectivity. Confusion of coding terms sometimes occurs in qualitative analysis. The terms node, index, category, code and theme can all be open to different interpretations (Morse, 2008; Gibbs, 2002) and I endeavour to explain these terms as I use them in this project. I use the following definition of a code: 'the most basic extract or element of the raw data or information that can be assessed in a meaningful way regarding the phenomenon' (Braun and Clarke, 2006).

By asking questions of the data, the coding process assists in the abstraction of specific characteristics or ideas (Richards and Morse, 2007; Graue and Walsh, 1998; Miles and Huberman, 1994; Strauss and Corbin, 1998). Coding allowed me to reflect on the familiar, the previously unseen, unknown or unfamiliar; but all now available for interpretation within one of the representational modes described above. Guided by the works of Richards (2005), Gibbs (2007) and Gibbs (2002), the assisted computer qualitative data analysis software programme, NVivo, version 7 (QSR, 2006) enhanced this data management phase. This package supports the creation and manipulation of codes (Gibbs, 2007), referred to within NVivo as nodes. These represent concepts or ideas. A number of folders stored the different sorts of imported data files, and I also made use of case node folders to retain a link to all the data on a specific case (Gibbs, 2002).

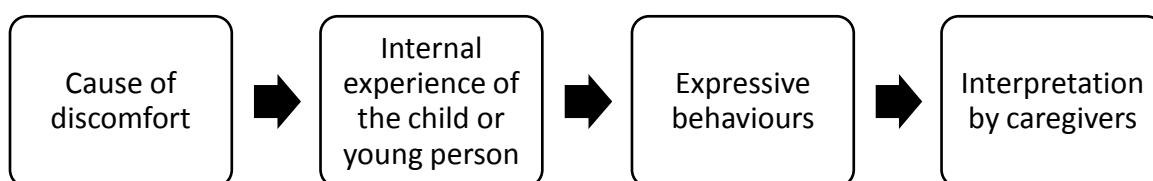
Initial coding of the data provided early opportunity to attribute a label to the descriptive information provided by the informants, including myself, about the child or young person's health condition, associated difficulties, adaptive equipment, adaptive functioning and communicative attributes. Early coding can nonetheless be a very descriptive process (Richards and Morse, 2007), but within NVivo it was possible from the outset to label and allocate the descriptive attributes about each case to a separate case node folder. This is in keeping with 'first orientation' as defined by Flick (2009) as the production of a short description of each case, which is continuously rechecked and modified during further interpretation of the case. This information was easily retrievable within NVivo using node or case-node search facility. The early coding

contributed to the descriptive parts of the case found in the extended case reports and the case displays in chapter 8.

Codes evolved and changed; sometimes simply a name change. More often, the new code label was a reflection of developing ideas because of data exploration, and examination of relationships between existing codes. Within NVivo, it is possible to use hierarchical branching structures of tree nodes, whereby a parent code may have one or two child codes, which may themselves be children to other codes (Gibbs, 2002). This was helpful as in cases of doubt, two codes can merge, but then reform, without deletion. As I was preserving case uniqueness, this process meant I had a combination of descriptive attribute codes, conceptual codes, categories and even thematic codes for the first case, before moving onto the second case and future cases.

Coding case attributes was more straightforward than the conceptual labelling of the data, but the latter was critical to progression. The assignment of coding labels within NVivo, and ongoing rearrangement of codes into hierarchies (Gibbs, 2002) involved two sources of thought: the questions asked during the conceptual, design and preliminary phases of the study, thus defined a priori, and the insights coming forward from the ongoing questions I asked of the data. Corbin and Strauss (2008) categorize the types of questions that can be asked of the data into sensitizing, theoretical, practical or guiding questions. This was helpful, for example, in the early stages if there was mention of discomfort I used the node, 'discomfort'. It was not until several codes accumulated with possible similar or dissimilar meaning did I begin to look at the analytical relevance, and then became much more rigorous in specifying code definitions through questioning. Examples include, is this a discomfort state? is this an indicative behaviour of a discomfort?; is this a perception of a discomfort state or state? I coded the observation and field nodes described in chapter 6 alongside the video data, but I acknowledge this data is of a different level: practices, situations and behaviours in the classroom.

Figure 7.1 Early Diagrammatic Model

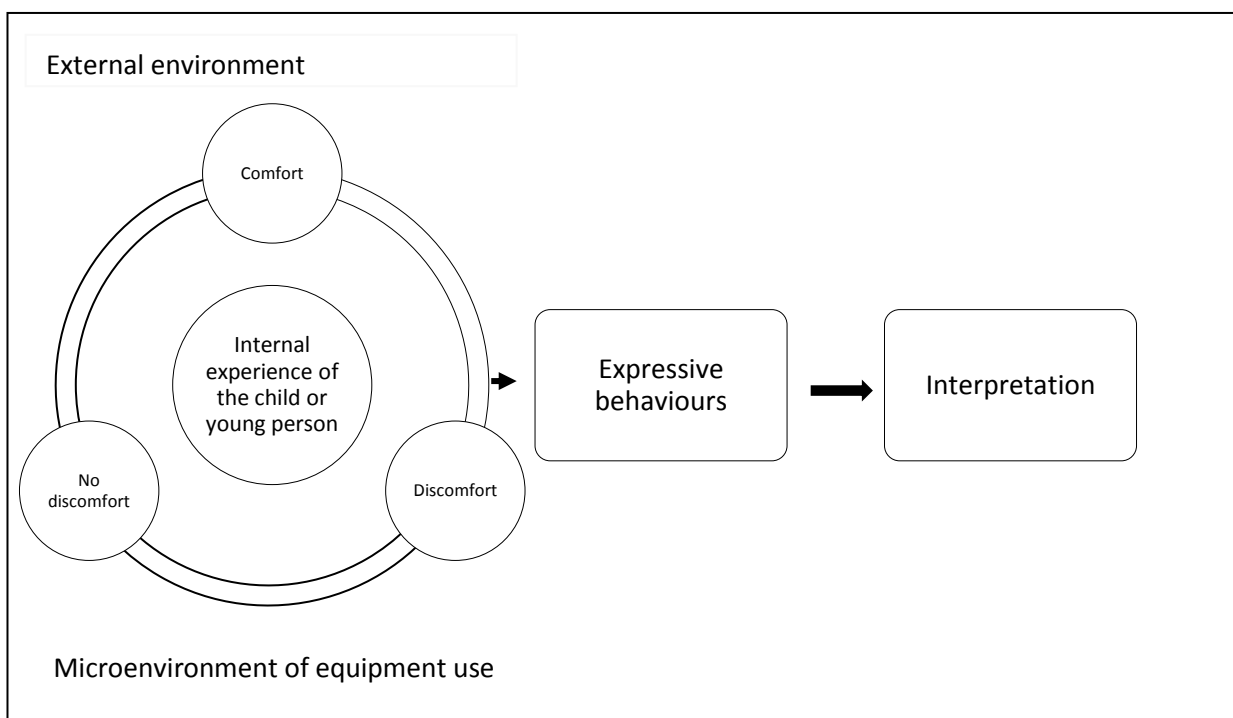


There was initial hesitancy that the theoretical and conceptual perspectives brought to the project would steer me toward a focus on the physical. At the stage of project

development, I had produced a diagrammatic representation of physical discomfort (Appendix 14), with one of my earlier models represented diagrammatically in Figure 7.1. In consequence, this did contribute to some of the labelling and coding described above, as I considered antecedent causative factors of discomfort for the expressive behaviours, including duration of equipment use.

Nonetheless, there were numerous other categories of coded data and the early model (Figure 7.1) soon became outmoded. Contextualisation of comfort was desirable and situation specific information about equipment use in the home and school environment was accumulating for coding. The initial model changed to take into account both comfort and discomfort (Figure 7.2). As I proceeded with the analysis this model kept me focussed on the topic of comfort and discomfort.

Figure 7.2 Comfort, Discomfort or No Discomfort

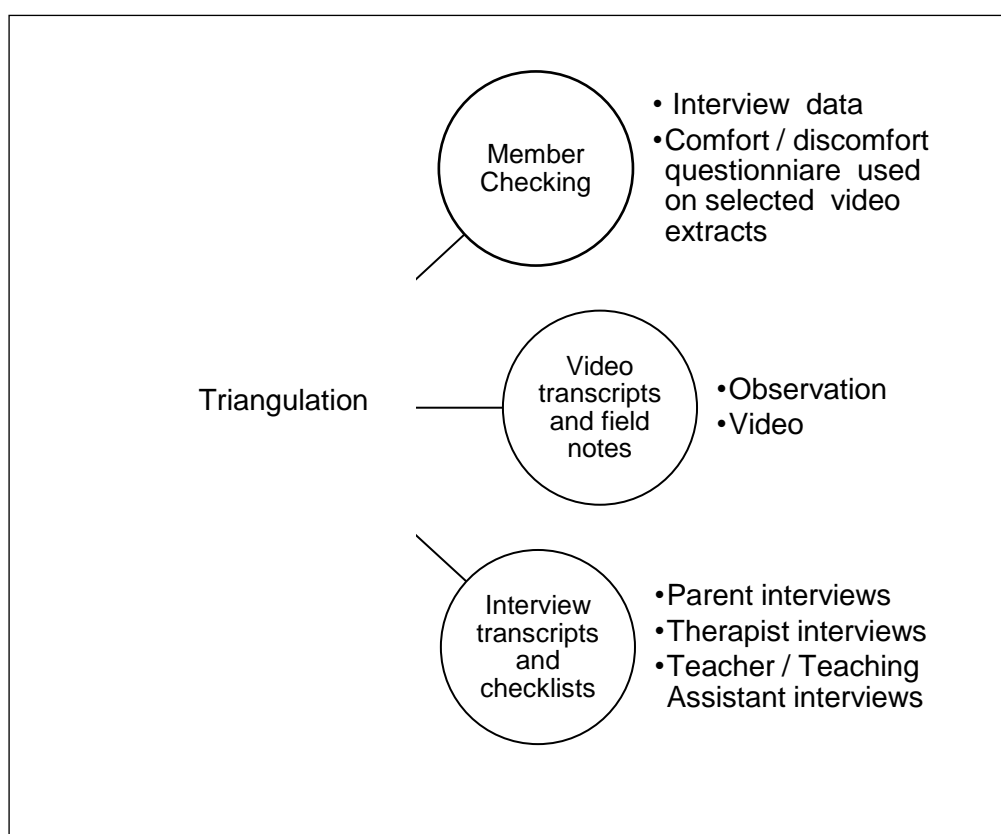


### Triangulation in analysing data

Before moving on to explain the deepening analysis of the case and cross case analysis, I return to the topic of triangulation. The implicit and explicit triangulation of methods is a feature of qualitative research, including its function in respect of quality. In a research design developed around its utility, triangulation is therefore an important topic. Triangulation in this study is the existence and connection of different sorts of data within the case study strategy. This is summarised in Figure 7. 3. It is methodologically sound as the combination of data sources and methods is in keeping

with the theoretical underpinning of the research perspective, and the research strategy, a proposition made explicit at the stage of research proposal. Flick's (2007, p.72) definition of intent 'to use the knowledge potential of two approaches systematically and to complement or extend them mutually' was helpful as I commenced data analysis.

Figure 7.3 Triangulation of data sources and methods



Data triangulation refers to the use of different sources of data as distinct from using dissimilar methods. This provides opportunity to analyse the interview data from significant others within the case, who all had some relationship with the child or young person. The interview data obtained from the significant others was all on the same level, the level of talking about experiences from a subjective point of view (Flick, 2009). A potential also existed to analyse this level of data across cases at a later stage. Triangulation of methods was my use of more than two data sources. In addition to the interview data, I had data from observations and video data. The different ways of collecting data had addressed different levels of the 'same' phenomena: subjective knowledge, classroom practices and professional knowledge. For linking the different sorts of data in the analysis, I looked at the level of the single case. Here I was able to compare the findings to see if they were convergent, contradictory or complementary.

## **Data displays**

Following the initial coding of the data, I used the sub-process which is described by Miles and Huberman (1994, p.91) as 'data display'. Here the data are organised and displayed in order to begin the process of examining and building a deeper understanding of the data. Making comparisons is an important part of any analysis as it allows the analysis to move beyond the descriptive level. However, as mentioned, I avoided making cross case comparisons too early. For each case, tables were composed of within case displays. In one table, I display key quotations from the interview transcripts, which relate to the non-verbal expressions. These data were of the same level, but derived from different data sets. Alongside this, I was able to display the information collected from the behavioural expressions checklists extracted from the NNCPC and PPP. (Appendix 11). Other tables include details of equipment use. Tables were useful in helping me lay out the data from such comparisons. NVivo searches retrieved the data to display in these tables, but manual searching of the interview transcripts also confirmed the content. Appendix 15 gives example of table displays. I also preserved the uniqueness of each case by producing case displays. These included data extracted from the different levels of data; for example, the interview transcripts. A vignette constructed from extracted field notes and the transcriptions from observation and video data was then included within each of these case displays. The observational data from the structured observations created the time charts also displayed in chapter 8.

## **Non-cross sectional organisation of coded data into meaningful groups**

As I moved forward into the next phase I had to review the relationship between the research questions, coded categories and other within case coded extracts of data. I was searching to bring coded extracts of similar characteristics together. Prior to this the codes appeared isolated. This stage involved frequent re-reading of the data to avoid loss of context. On occasion, a node name change was necessary as I wanted to represent more fully the meaning of the data extract. There was some merging of coded labels and coding of new ideas to represent developing thought processes. Within NVivo, the use of node trees assisted this data organisation (Gibbs, 2002). Figure 7.4 provides example of an NVivo tree node labelled 'cause of discomfort'. Of note here is the coding of data 'other causes', and 'aesthetics'. Removal of these free nodes from this tree node took place at a later stage because restriction, fabrication error, positioning error and stretch appeared physical in origin. Further examples can be found in Appendix 16. Early formation of a tree node labelled 'cause of comfort' was



sparse in comparison; aesthetics and postural position were the only two nodes that at first sorting appeared 'to fit'. The antecedents of comfort developed with further analysis.

Figure 7.4 NVivo Tree Node Cause of Discomfort

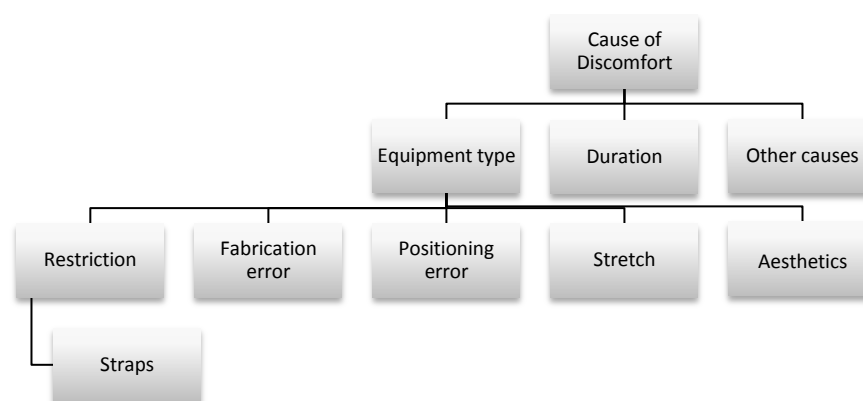


Table 7.1 provides a summary account to a second sorting of the data for one of the earlier cases. At this stage, these groupings included both tree nodes and free nodes. For example, the significant others spoke of child or young person 'likes' and 'dislikes', often in the context of equipment use or non-use. I did not merge these free nodes into 'cause' tree nodes as source data at this stage appeared disparate, yet it warranted categorisation alongside causes. Although all data groups were provisional following this attempt, two groups appeared very broad in nature, one simply labelled 'context', the other 'noteworthy instances'. This sorting, sometimes known as categorical sorting (Miles and Huberman, 1994), opened up opportunity for further examination of relationships within the data. A first attempt to achieve this following initial sorting produced the complex memo found in Appendix 17; greater clarity was necessary. Previously labelled and coded events were not immediately recognizable as influential. For example, 'circle time', a class activity at the beginning of each school day, coded 'group activity'. However, Miles and Huberman (1994, p.111) prompted me to look more closely at 'illuminating processes' which later aided my interpretation of comfort.

I had to triangulate codes which were based on perception of retrospective interpretation and video interpretation codes, and the next stage, prompted by the writings of Strauss and Corbin (1990, p.61), was a noteworthy step in the right direction. They summon up the notion that coded categories have conceptual power because they are able to pull together around them 'other' groups of concepts or

subcategories. Each category retains its own properties with dimensions represented along a continuum.

Table 7.1 Second sorting of coded data extracts from a single case (1) case

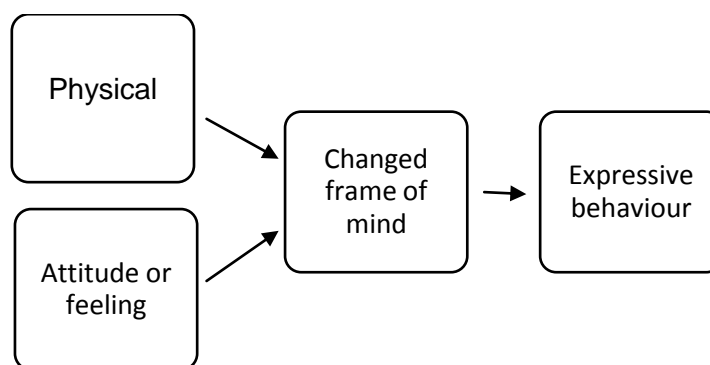
<b>Causes</b>	<b>Expressive behaviours</b>	<b>Underpinning interpretation</b>
Physical Restriction Fabrication error Positioning error Duration  Desirable sensory stimulation Like Dislike Choice Aesthetics	Facial expression Body movements Whimpers, screams, cries Comfortable Uncomfortable Discomfort Behavioural response Happy, content ,calm Unhappy expressions Distressed Neither Pain	Intuitive knowledge Experience Parenting Unknown Routines Process of elimination Consideration of health need [Compassion] [Persistence]
<b>Context</b>		<b>Noteworthy 'instances'</b>
Equipment use Equipment non–use School Home Transport Curriculum one to one engagement One to one engagement Named activity Whole school group Therapy  Assembly		Other children Being in a relationship with another Decisions Engagement within context Acceptance Movement [Freedom to move] Positional change Issues of parenting and Professional culture Routines Avoidance

I had grouped physical causes and feelings together. Feelings of like or dislike arose from the significant others' interpretation of situations, sometimes explicitly related to a cause, hence the grouping. Some clarity was desirable. What was I interpreting as constituting a cause? The current codes within the group 'cause' initially appeared mismatched. By asking a number of questions, properties and dimensions became clearer

- Is this a cause of a potential internal experience, which might result in a frame of mind?
- What is subject to interpretation? Does this extract of data represent an illuminating event that was previously subject to interpretation?
- What underpins interpretation by others?

A cause or antecedent, whether it is physical or other, can potentially result in a changed 'frame of mind' or 'mood'. This 'other' may be a consequence of an attitude or feeling. 'Dislike' or 'like' are attitudes or feelings, following consideration of something that may be either disagreeable or pleasant (Figure 7.5). Like and dislike as related by the interviewees were probably the consequence of a previous interpretation of a 'frame of mind' due to knowledge of the child or young person's disapproving or approving feelings from the past. The question 'what actually is subject to interpretation?' then allowed me to separate out the frame of mind from the expressive behaviours. Nonetheless, frame of mind or state of mood was still subject to interpretation through behavioural expression.

Figure 7.5 Antecedent of potential internal experience



Is this a cause of an experience? This question pressed me to examine situations where the child or young person appeared happy and contented, or where others had attested to this state of mind in the interviews. To give some focus to the internal experience of the child or young person meant going back to the data to look more specifically at the data grouped under the heading 'context'. Situational events would be contextual; however, there would be differences because of the data sources and the group of significant others involved, including the researcher.

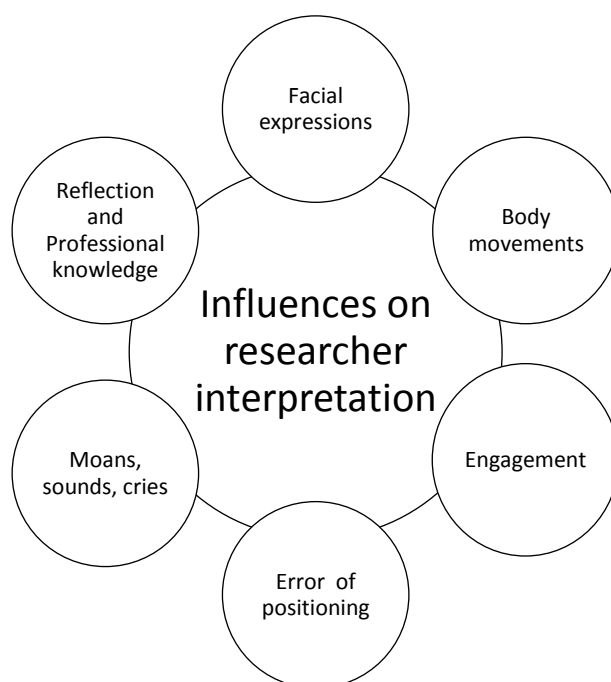
One way or another more in depth examination was necessary to achieve greater understanding. This is because there were still a number of unanswered questions. Was a distressed state in a child or young person due to dislike of the situation, or was it due to a physical discomfort? Was a happy state due to finding a situation pleasing, or was it due to having physical comfort measures met, or simply was there no physical cause of a discomfort?

Asking the question, 'what is actually subject to interpretation?' challenged my thinking; it was particularly helpful as I grouped expressive behaviours, whether expressions others related to comfort or discomfort experiences, happy/content expressions,

distressed expressions or pain. In response to past situational events the significant, others had interpreted the behavioural expressions of the child or young person. They had knowledge of the situational events influencing behaviours. I myself had become a participant; what was it that that influenced my interpretation as I analysed the video data? I was very aware that in the first instance I had looked at the facial expressions, alongside whimpers, cries and smiles. These were obvious in video files I selected for member checking. I had made an interpretation of the child or young person's mood, based on these expressions.

In editing files for member checking I was able to remove context, leaving only the facial expressions. Yet, I myself had developed personal interpretation from other contextual influences. In particular, the point I started to think about comfort and discomfort as opposed to state of mind, a number of other influences arose through a process of critical self-reflection. Were there positioning errors, was the child moving, and how did the postural position compare with my own professional view of good postural management? In effect, I was searching for clues; similar to those used in practice, and like the respondents I used a similar process. 'Elimination' was already a coded data category within the interview data.

Figure 7.6 Influences on researcher interpretation



External and internal factors influenced the reasoning taking place (Figure 7.6). Yet in analysis of the video data, other than documenting my findings, I, unlike the other participants in the research, did not have to make a decision or take responsive care giving actions. This was not so for the significant others. The events, interpreted by the significant others and described through interview discourse, result in decisions and actions which warranted further analysis to aid understanding.

Some coded data extracts, now referred to as sub categories-of data, within the 'context' cell of Table 7.1 then became 'events' within a defined context, and a separate cell was established for coded categories labelled action or outcome (Table 7.2).

Table 7.2 Sub-categories

<b>Physical (restriction)</b> Fabrication Duration [unwanted sensory stimuli] Desirable sensory stimulation	<b>Expressive behaviour</b> Facial expression Body movements Whimpers, screams, cries Behavioural response	
<b>Attitude or feeling</b> Like Dislike	<b>State of mind</b> Comfortable Uncomfortable Discomfort Happy, content, calm Unhappy Distressed Neither Pain	
<b>Events within a defined context</b> With equipment Without equipment School Home Outings Transport Curriculum one to one engagement Named activity Circle time Curriculum class participation Therapy Assembly Lunch time /Snack time, Morning/lunch time break	<b>Noteworthy 'instances'</b> Other children Being in a relationship with another Decisions Engagement within context Acceptance Movement [Freedom to move] Positional change Issues of parenting and professional culture Routines	<b>Actions</b>  Communicative interaction Positional change  Movement Fidgeting Postural management

In summary, the previous sub-processes were beginning to aid understanding. Emerging from the analysis were key elements of the particular and holistic parts of the data for each case. There was greater transparency of cause, attitudes and feelings,

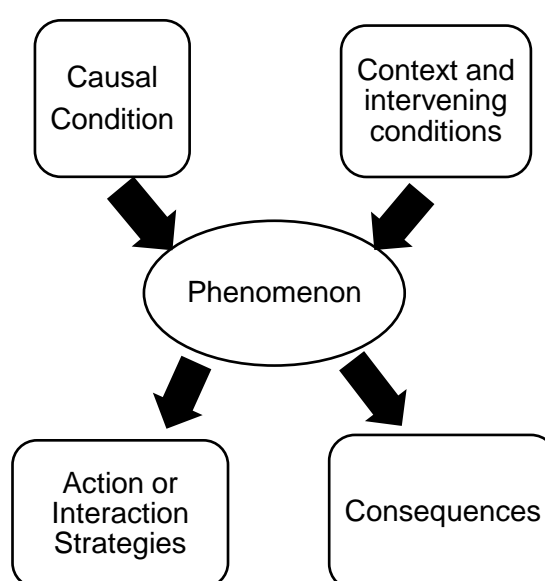
state of mind and relevance of situational events. It is important to remember that these key elements relate to the research questions; however the data within is still contextual and holistic to each case and not cross sectional. Thus for each case, I was beginning to make sense of the data generated. Event listing provided the framework to reconstruct narrative case reports. Miles and Huberman (1994, p.11) call this form of data display an 'extended text'. These, alongside other displays, become the content of the next chapter.

In Table 7.2 nodes not found in Table 7:1 correspond to those added. As the analysis of the cases, progressed new descriptive attribute or conceptual codes added to these sub-categories of data for cross case exploration. 'Stretch' and 'distraction', for example, were code labels only commenced during the analysis of case three.

### **Making progress**

Through these analytic procedures, the first case analysis resulted in the development of a number of grouped coded categories, stored within NVivo as 'sets', but to achieve enhanced and reasoned interpretation I continued with a similar strategy of questioning. On this occasion, I used the Strauss and Corbin (1998, .p.130), coding paradigm tool to assist. I adapted the diagrammatic version (Figure 7.7) from Flick (2009, p 311)

Figure 7.7 Paradigm tool, adapted from Flick (2009, p.311)



Specifying features within the tool give identified phenomenon precision, and link it in a set of relationships. This tool helped me probe the mounting ideas following first, second and subsequent sorting. I used the NVivo sets sorted under 'frame of mind' as 'phenomenon' because here was the location of codes initially labelled as 'comfort' and 'discomfort', alongside the 'frame of mind' coded categories of 'happiness', 'unhappiness', 'contentment' and 'distress'.

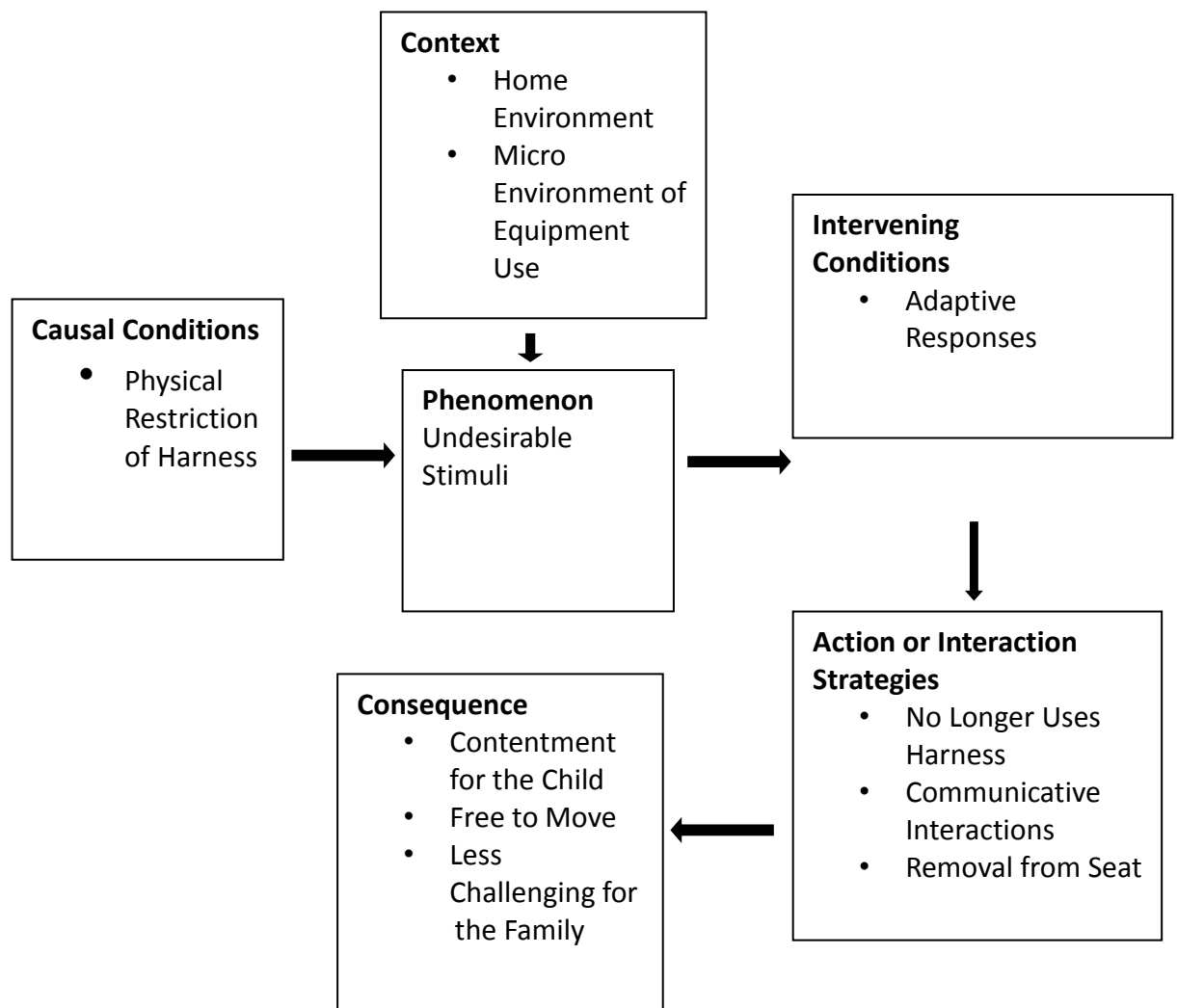
This tool was the basis for the following questions, which prompted me to look again at the pre-conditions and circumstances surrounding situational events related to equipment use as conceptual clarity was still lacking; 'frame of mind' still included data coded comfort and discomfort. It was important to make the specifying features of the grouped categories of data explicit:

- **Phenomenon:** what is the data referring to, what is the action or interaction all about?
- **Causal condition:** what is the event or incident that leads to the occurrence or development of the phenomenon?
- **Context:** where is the location of the event? Was adaptive equipment involved? What else was taking place?
- **Intervening conditions** what are the broad and general conditions bearing upon action and interaction strategies?
- **Action and interactional strategies:** how is the child responding? How do the significant others respond? Which strategies are explicit/implicit when there is a discomfort or comfort component assumed, mentioned and attached to a situational component of an event? How are behavioural components confronted or anticipated? Where there is interaction in a situational event, who acted and what happened? Is the child or young person active or passive? How is the child or young person noteworthy?
- **Consequence:** What changed? What was the consequence? What is the resulting action? Is the assumed discomfort or comfort of the observed or recalled events the consequence of an action? For example, when the distressed child was removed from the equipment and this was followed by the appearance of a happy smiling face. Is the assumed discomfort or comfort of an observed or recalled event a cause of an action or response? For example, does someone respond by repositioning the child?

By reflecting on these questions, I was able to formulate further assumptions about the strategies of the child or young person and the strategies of the significant others. Thus

far, the child or young person the outcome of that experience and the role of others within that experience had been on the margins of the analysis. This phase addressed the imbalance. For example, if the causal condition of restriction is an internal physiological response, the expressive behaviour was prompted by the intervening factor, an adaptive response, this being interpreted by the caregivers and responsive action taken. The consequence may be a state of ease or contentment, one type of comfort (Figure 7.8)

Figure 7.8 Causal Condition of Restriction



The child, young person and significant others respond in some way to a comfort/discomfort experience imposed by equipment use; the action that is taken is purposeful, may be behavioural, interactional or reactive. In some circumstances, there may be no response. There could be facilitation or constraint on these actions by intervening conditions (time, burden, curriculum, family life). Strauss and Corbin (1990) further point out that consequence may be actual or potential, happen in the past or the

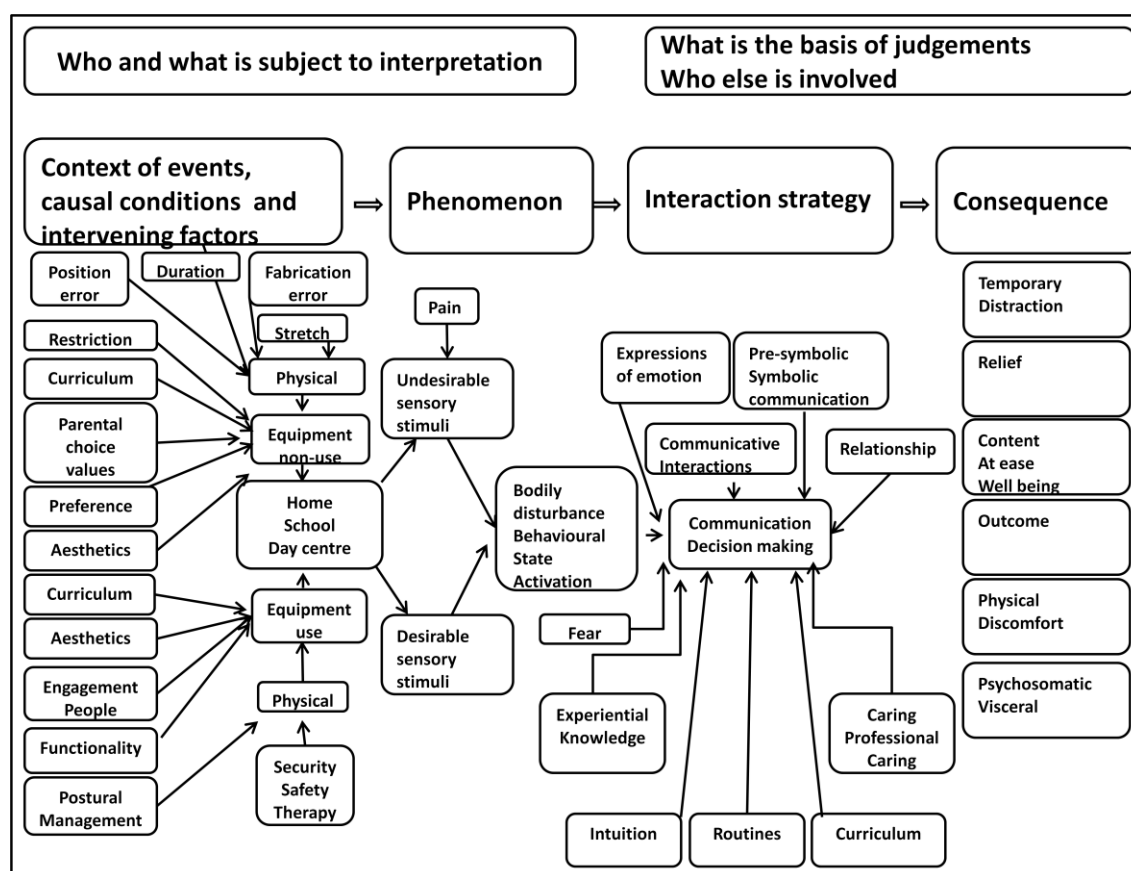


future and that a consequence of an action at one point in time may become part of the condition for another, affecting the next set of actions or interactions occurring in a sequence. I then re-grouped a number of categories previously grouped in other locations under consequence. Figure 7.9 below displays the categories woven into this model.

### Cross case reviewing of categories

I subjected the categorical map developed from the first case to reassessment for all further cases using the imposed structure of the paradigm model. I retained the overarching thematic groupings, whilst leaving the analysis open to further elaboration of sub-categories, the product of comparison of within case data sets, and case-by-case comparisons, which enabled insight into the typology of cases for presentation of findings. The outcome of this stage was an overall set of grouped coded categories, sorted thematically. Comparison helped me understand the developing relationships between phenomena, settings, events and cases.

Figure 7.9 Category regrouping



## **Thematic development**

Up to this point, I referred to causative factors, attitudes and behaviours, expressive behaviours, frame of mind, actions (strategies of child/ strategies of others) and contextual events as grouped categories of coded data. Use of the paradigm model pressed me to refocus my analysis on the broader level of thematic development. Coded data differs from units of analysis known as themes. A theme captures something important in relation to the overall research question, a meaningful essence that runs through the data (Morse, 2008; Braun and Clarke, 2006). Use of the paradigm model demonstrated the cohesive and meaningful potential of my data, and some of the grouped coded categories blended easily into this imposed structure, coming together as an overarching theme or sub-theme. Yet elsewhere some refinement of the themes was necessary. I reworked grouped coded categories, and developed sub-themes. Table 7.3 shows that initially I had grouped 'patterns of action' as an interactional strategy alongside the 'decisions and interpretation of the significant others'. These coded groupings I could have blended to become sub-categories of the final theme, 'the contribution of others to the experience'. However, on closer examination of these patterns of action, I renamed these 'antecedents of comfort' as these were the actions taken by the significant others to achieve comfort. By regrouping 'antecedents of comfort' this meant I had to move the categories grouped 'child or young person, responding, engaging, functioning or participating' to become a sub-theme of consequence.

Table 7.3  
Grouped  
categories  
subthemes  
and themes

			Grouped categories of data			Sub-themes			Theme
Who is subject to interpretation?	Phenomenon	Child or young person's responsiveness or an expression of emotion or feeling?	Behavioural responsiveness Communication Facial movements Facial expressions Movements and postures; sounds, symbols; eye contact			Responsiveness to internal and external events Behavioural expressions: facial, vocal, bodily Communicative interactions			The experience belongs to the child or young person
What is subject to interpretation?	Contextual events, causal conditions and intervening factors	Events in the external environment or the microenvironment of equipment use Internal bodily process	Restriction Stretch Fabrication Positioning errors Duration Fatigue	Aesthetics	Child or young person engagement functioning participation responsiveness	Antecedents of comfort and discomfort			Understanding the contextual clues
Who else is involved, how and what underpins judgements about equipment, comfort, discomfort?	Interaction strategies	Parents Teachers Classroom support assistants Key workers Therapists	<b>Decisions and interpretations</b> Communication Anticipated decision Process of elimination Decisions based on knowledge of child / young person Decisions based on events Decisions based on organisational culture Curriculum, care plans, safety Intuitive knowledge, experience Parenting, parent knowing their child , having a relationship Caring attentiveness		<b>Patterns of Action</b> Avoidance, compromise, restrict use Postural management Postural repositioning Movement		Classroom routines Family routines Home is home Knowing the child /young person Parenting and caring		The contribution of others to the experience
Consequence of favourable and unfavourable stimuli			Physical Discomfort Psychosomatic Visceral Aesthetics Comfort			Relief Ease Contentment Functionality	Distraction	Discomfort Restricted use	Consequence: comfort and discomfort: connected and independent

## Conclusion

In this chapter, I have presented strategies, which allow me to manage and promote quality in this research project. I have made the modes of representation, sub-processes involved in the management and retrieval of data for each of the separate data sets, data triangulation and triangulation of methods explicit. Early coding was a useful means of managing the data, and one advantage of NVivo was the easy retrieval of contextual data about a case. This was important for the reconstruction of case reports forming part of the content of the next chapter. The analysis had to be congruent with method and to preserve the uniqueness of the cases I embarked on a within case, then cross case analysis. NVivo allowed examination of coded categories and other within case coded extracts of data. As I commenced cross case analysis categorical sorting opened up opportunity for further examination of relationships across data levels, data sources and cases. Use of the paradigm tool by Strauss and Corbin (1998) demonstrated the cohesive and meaningful potential of the data, and grouped coded categories came together as an overarching theme or sub-theme. I have elected to present the findings in two chapters to enable the analysis to remain sensitive and open to the specific contents of each individual case. Chapter 8 presents the cases and chapter 9 presents across case findings. In chapter 9 aspects of the data for each theme are organised with accompanying narrative with the purpose of capturing the essence of each.

## CHAPTER 8

### WITHIN CASE FINDINGS

#### Overview of the chapter

The physicality of another person's discomfort experience was the mental picture I held as a physiotherapist. Tacit and experiential knowledge had led me to believe that those children and young people who use language would, if given the opportunity to do so, express views about the comfort of their equipment. Concern remained for those without this capacity. It would be impossible for me to give 'true voice' to these children or young people; interpretation of expressive behaviour as representation of the child or young person's inner experience was potentially an important consideration. With this in mind, the research questions restated below framed the study and the findings generated which I will now elaborate on and present.

- How does the child or young person communicate the experience allied to positional comfort or discomfort?
- What are the antecedent factors and attributes of equipment comfort and discomfort?
- How do these relate to duration of equipment use?
- How do others who are part of the social life world of the child / young person interpret comfort and discomfort?

The intention is to use three separate chapters to give meaning to the case data within the context of comfort and discomfort. In presenting the findings of a qualitative case study there is the need to keep the description close to the original data and do justice to case uniqueness. I therefore intend in this chapter to present a synopsis of each case in turn. This will contribute to the analytical audit trail and demonstrate where I attached interpretative meaning to the contextual data. In chapter 9, I illustrate further interpretation using cross case analysis as this enables exemplification of similarities and differences between the cases. Here I make use of the themes arising from the analysis to express the essence of comfort and discomfort. The structured approach to the analysis adopted comes to fruition in chapter 10; here I discuss the accumulative categories and either substantiate or contrast them with ideas presented in the literature.

For the synopsis of each case, I will vary the format of presentation to make this chapter less repetitive. For six of the cases I use case narratives to represent the

voices of 'others', those participants in the research who spend significant periods with the children and young people. Due to my interpretive responsibilities as the researcher, I am necessarily included as an 'outsider voice' in these narrative constructions. I will include in this sample, one child in transition to primary school, two children attending primary school, two children attending secondary level and one young person attending day services, ensuring within the sample there is a mix of children and young people who move too little or move too much<sup>4</sup>. I give thought to the inclusion of those interpreted data sources, which help illustrate the child or young person's behavioural and expressive responses to situational events as they relate to equipment use. For the remaining cases, I use case displays. These include findings extracted from the different levels and sources of data; for example, the different sources include quotations from the parent, teacher or teaching assistant and therapist. A vignette within each display is then constructed from extracted field notes and the transcriptions from observation and video data.

Authentic research requires detail to make it real. There is commitment to illustrate the uniqueness of each case, but only in respect of the set aims of the research and the established ethical framework. I have used pseudonyms' for all the children, young people (Table 8.1), and I have refrained from naming the schools or day services involved. The other conventions used to link the narrative to quotations from interview transcripts, observational and video data and field notes I document in Appendix 18. To provide an overview before moving on I have clustered some particulars together in the following paragraph.

### **The children and young people**

In the course of this study, I made visits to the family home and interviewed parents. In the primary and secondary special needs education schools, I spent time in the classroom observing and taking video of the children and young people. I interviewed teachers, teaching assistants and therapists, and further extension of this work allowed access into a day service centre for people with learning difficulties. The sampling strategy had specified children or young persons with a co-impairment of severe or profound learning difficulties who were unable to communicate through the more usual verbal route. In all, thirteen children and young people became the focus of this study. Five of the children were receiving

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<sup>4</sup> Child or young person who moves too much: variable tone , unwanted movements  
 Child or young person who moves too little : stiff limbs that resist movement, hypertonia, static postures

their primary education within a special needs school (Key Stage 1 and 2, ages 4-11), and four of the young people receiving secondary education within a special needs school (Key Stage 3 and 4, post 16 ages 11-19) for pupils and students with special needs. The two pre-school children commenced full time education at the same primary school during the course of the study, and the two young adults in the study attended a day service centre for people with learning difficulties. All pupils in the study had a Statement of Special Education Needs (SEN) and a learning programme specifically designed to meet the needs of the particular child or young person within his/her school. Within school P-level attainment targets where pupils work below level 1 of the national curriculum (Quality Curriculum Authority [QCA], 2009) were in use. A care plan was in place for the two young people attending day services.

Table 8.1 Pseudonyms of children and young people and additional clinical and management details

Case	Pseudonym	Hoist Transfer	Epilepsy	Gastrostomy	Frequent admission to hospital	Past surgery	Rudimentary form of non-verbal communication	Comply with a simple request
1	Elizabeth	•	•		•	•	•	
2	Hannah		•				•	
3	Peter	•						•
4	Susan	•			•	•	•	
5	Nicola	•		•	•	•		•
6	Janet	•	•			•		•
7	Aiden			•	•	•	•	
8	Stephen		•				•	
9	Ellie						•	
10	Dominic	•		•	•	•	•	
11	Phillip	•	•			•		•
12	Vikki	•				•	•	
13	Brendan	•					•	

Inclusion criteria specified the need for the child or young person to use some kind of special or adaptive seating, and or other items of positioning equipment as

recommended and individually adjusted by the therapist involved with the family. It was not the purpose of this study to compare or contrast equipment. New equipment comes onto the market regularly, and the equipment changed during the data collection period for one of the children. All the children and young people had a neurodevelopmental disability; seven families had been given a diagnosis of cerebral palsy in relation to their child, others a neurodevelopmental disability of chromosomal or syndromic cause origin. In addition to the pre-specified domains of posture and movement, cognition and speech and language involvement, a number experienced seizure disorders and deficits in the processing of sensory information. Deficits in the basics of postural control and dysfunctional processing of sensory information accounts for difficulties in postural activities in those with developmental disorders, but with the exception of CP current knowledge is limited (Hadders-Algra and Carlberg, 2008). Janet functions at GMFCS 1V, but all the other children and young people in the study with CP function at GMFCS level V. In addition to a specified need for educational provision, all the children and young people received supported in relation to individual health and social care needs from partnership service agencies. All the children and young people lived in the family home; respite was an option which some of the families used. Table 8.1 gives additional case information.

## **Dominic**

### **Box 8.1 Ideas and perspectives evolving from the findings for Dominic**

Posture managed but passive in equipment; often looks content
Responds to internal bodily events, very subtle response to external events
Repositioned several times during the school day, as he does not appear to respond to errors of positioning
Distresses not usually equipment related, but previous difficulties.
Legs left free to move in home chair
Family accepting of the benefits of equipment
Established family routines and parent response to distress

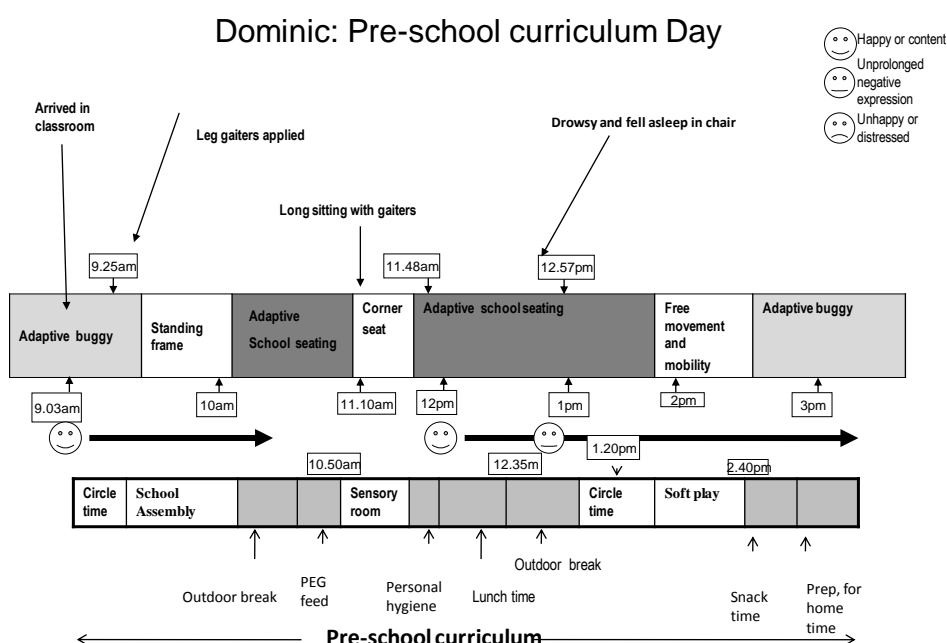
The findings for the first case I present come from Dominic, one of the pre-school children attending school on a part-time basis. Dominic was present on all the visits I made to the home, except the final visit. On these occasions, Dominic was



always in his adapted chair. The day I interviewed his mother he sat in front of the television. He looked contented, but his responsiveness to the television was not immediately perceptible. At school, I observed all interactions and activities with him in the classroom, his responses during assembly, in the dining area, outside at morning and afternoon break and in the multisensory room. In this context, I saw variety with regard to postural position and equipment use.

Figure 8.1 provides an overview of one school day with regard to positional change, adaptive equipment used and the type of curriculum activity taking place on the day I observed him in school. On this school visit, there was only one point during the day his expression changed from a content or happy expression. This was just before the end of lunchtime break as identified in Figure 8.1.

Figure 8.1 Observation of a school day



On the day I recorded video, for his music lesson his position was a prone lying position over a wedge, with his legs positioned in gaiters. He used the standing frame and adaptive seating for periods similar to that identified in Figure 8. Others reported Dominic as a sleepy child, sometimes difficult to rouse, with little movement, very low tone and visual problems but known on occasion to track bright, visual, auditory stimuli. During circle time I witnessed attention and a changed facial expression with one to one teacher engagement. Dominic used his standing frame during assembly and I interpreted his enjoyment of the music and

singing from his facial expressions, which varied between contentment and smiles. Only on one occasion did I witness Dominic in distress (10v10), moaning and whining soon turned to inconsolable crying; on this occasion a bowel movement, an internal bodily stimuli, validated his distress. The staff had worked this out through a process of elimination. For his personal hygiene to be addressed, he was removed from his adaptive seating and on return became contented. By the time he was back in class, he had fallen asleep

As one of the younger children in the study, Dominic and his family have the added assistance of contemporary equipment design features. His current home and school adapted seating chair has many adjustments; it tilts in space and adjusts to floor level. The fabrication and colours are far superior to the black vinyl used in the past for the manufacture of mobility equipment. I remember thinking equipment had come a long way since the 1970's. Dominic could be at floor level with his siblings and peers in the classroom; then for care-giving tasks, adult interactions and social mobility, the chair could be readjusted. The tilt feature used gravity to assist his postural control. I observed Dominic to be content in this equipment; his physiotherapist also reported that 'he is quite passive in all his equipment and goes into position quite well' except if something else is going on and he is generally unwell. Dominic may appear passive; however, technical design errors in the past have caused Dominic distress, sufficient to warrant use of a beanbag, instead of adaptive equipment. The chair in use at the time was too upright and interfered with his PEG tube. This positioning difficulty also became evident whilst prone standing in a frame and prone lying over a wedge. The therapist indicated this response had become a learned response, with an unhappy expression occurring even during the pre-preparatory period. Dominic's mother found herself placing him on the bean bag more and more; however new equipment, parental response and subsequent regular attentive repositioning at school have avoided repetition of this positioning related discomfort.

Dominic's mother was accepting of the equipment. The family asked for physiotherapy when he was 3 months; they got rolls and mats, corner seats and an adapted upright infant chair. His current chair he now uses frequently, although he had to go through an adjustment period. His mother also described how he objected when she placed him in the chair and do his physiotherapy exercises, but 'then I watched him when the physio's did it and he objected to them, it was just his way of saying he didn't want to do it'. Mum says:

In the early days, he could only manage maybe 10 or 15 minutes because he hasn't got very good muscle tone and he would flop forward. So, that's when we got the beanbag for when he wasn't strong, or if he wasn't well. But then since we've got this chair he can stop in this all day if he wanted because you can just tilt it back when he starts flopping or when he's got to work we put it right up. Overnight if he is not sleeping in his bed, if he's awake he comes down and goes in there (10Pi1:4).

Dominic's mother believes he is comfortable in his current chair, she explains:

Sometimes when he's lying down he tries to sit up and I don't know whether he keeps bashing his head and he gets upset or whether he's getting frustrated because he can't sit up and then you put him in a chair and he's happy in that sitting position and that seems where he's happiest (10Pi1:1).

The foot straps and the knee blocks tend not to be in use at home because his mother feels that he likes to have a good kick. I witnessed Dominic's contentment with this movement, which did not alter his postural position. His mother feels that if he has them on in school this is fine. Dominic's mother spoke of his discomfort in lying. He requires regular repositioning at night, but currently does not use a sleep system. I asked her how she knew he was uncomfortable:

Yeah, I've learnt now, because he goes from like a laugh to a whine and once he seems to go to the whine I know then that he's going to start crying and then we go to him before he starts. We brought him down at half one this morning because he just wasn't settling in his bed and we held him sitting up and then he went to sleep on his beanbag (10Pi1:1).

Even though Dominic's mother is very responsive to his needs both day and night, she does accept he gets bored

Yeah because you go in and he'll start laughing again he just wants your there, as soon as you walk out he'll start again and you go back and he just laughs which is great but at 2 o'clock in the morning it's not (10Pi1:11).

## **Elizabeth**

Elizabeth fulfilled the inclusion criteria, being the first child for whom all the ethical procedures were in place thus enabling me to commence the study. Not the child with the restricted immobility I envisaged, Elizabeth challenged my thoughts from the very beginning. Elizabeth attends a special needs primary school. We first met when I visited the family home to introduce the project. She was sitting in a supportive, adaptive armchair in the living room. I introduced myself; she appeared in her own little world preoccupied with the sensory stimulus because of hand to

mouth play. As the family meeting progressed, I noticed Elizabeth had gradually managed to twist herself sideways in the chair, so her legs and feet were over the padded armrests; she sat sideways in the seat. The finger to mouth activity continued, she appeared oblivious to the changed position. A lap belt stopped her falling out of the chair; the foot straps remain unfastened. She appeared content. I would eventually spend more time with Elizabeth and soon discovered that in physical terms she just moves too much. She lacks core trunk control and has large range uncontrolled limb movements together with frequent atypical facial movements. Elizabeth should have been at school on the day I visited, but she had had loose motions the previous day and was unable to attend because of the school sickness policy. Absence from school was frequent, mainly due to uncontrolled epilepsy. In her childhood years thus far, she had spent much time in hospital. These were difficult times, but made worse by lack of equipment in the hospital setting.

#### Box 8.2 Ideas and perspectives emerging from the findings for Elizabeth.

Others perceive Elizabeth to be happiest free on the floor, does not like movements restricted

The floor is a position used often at home

Inclusion: with opportunities for sensory engagement (watching, listening) she tolerates other positions. This includes less supportive positions.

Seating is necessary for care and educational inclusion

Chair design features influence perception of comfort and discomfort

The teaching team and parents respond readily to discomfort cues, and do not like to see her in a state of distress.

Positioning options are child / curriculum driven.

The contact I had with the school staff accumulated over time. I visited school on separate occasions to interview the educational and therapy staff involved with Elizabeth and again during the period of observation and video recording. Across the three levels of data, descriptions of Elizabeth's expressive behaviours had similarities. Finer distinctions were challenging for myself as I did not have the close relationship in comparison to the significant others. On each occasion when I introduced myself to Elizabeth and talked to her, initially I was never sure that she acknowledged my presence, but reviewing the video data at a later point I believe

confirmed an awareness of my presence (1:v4). On more than one occasion, I recorded Elizabeth as appearing happy.

Life with Elizabeth was not easy; the parents and school staff had experienced a number of problems with sitting, however, the need for seating in the home or school not questioned. Her father said 'can't sit her on lap for feeding – just too wriggly', and Elizabeth's teacher explicitly portrays some of the advantages of her adaptive equipment:

She is more focused. When she's sitting in her school chair and she's got her tray in front of her, she's looking at me, she's giving me a whole load of eye contact, she's smiling, she's giggling, there's a tray so we can put things on, we can interact with her and kind of she's right in front of me and I'm right in front of her but when she's on the floor she shuffles away, She kicks, she moves her head, she's looking around the corner, she doesn't have that same interest, she's not motivated to be doing anything because there's other things that interest her more like shuffling across the carpet and being out (C1Tei21).

Nonetheless, Elizabeth was portrayed as a child who sometimes had a temper when it came to sitting tolerance. The physiotherapist admitted 'if I am honest. I think she just doesn't want to be sitting down' and 'Elizabeth has her moments, a right paddy' were words used by father. Similar words were used by the class teacher:

She would have a paddy, we would find it really difficult to get her in[the chair?] because she would arch her back and like throw her head back and her arms and legs would kick out and lash out and she would cry and she would have what you would call a 'paddy' in a toddler because she didn't want to go in her chair and it would be quite stressful putting her in because it would need 2 adults and sometimes 3 adults to keep her, to be able to keep her sitting whilst we fastened all the straps up, but it was stressful on us as well, we didn't like seeing her, you know she was having this huge paddy getting her so upset, she didn't want to go in the chair and we were basically making her go in it. So it was quite stressful to us and we didn't like (1Te1:5)

In the family home, I made a comment about Elizabeth appearing happy in the supportive armchair and asked how long she would stay in the chair. Mother replied, 'it depends on mood'; father continued 'if in a good mood, she could stay a couple of hours'. Then mother 'in good mood, uh uh, but then she stiffens ups'. Father 'she likes to be on the floor, likes doing circles on the floor'. They did not dismiss the sitting position. Father had contributed his views to the design of a suitable harness

for Elizabeth's home chair. This did not work well for the family (Table 8.1), and the school struggled with the amount of restriction provided by excess straps.

Table 8.2 View's about Elizabeth's Adapted Seating

Father	Teacher
<p>Father: It was like a chest harness and she just didn't like it, you know. I actually thought of it and asked them to design it in. We got it designed in, but she didn't like it. But it wasn't suitable.</p> <p>Interviewer: You say she didn't like it. As Elizabeth's parents, what was it, why do you think she didn't like it? You thought it was going to be the answer, but obviously, it wasn't. You haven't got it on. Why do you think she didn't like it?</p> <p>Father :She just doesn't like been tied in</p> <p>Mother: She had a real paddy, tears, red face. And then we took it off we had smiles</p>	<p>We wondered if that chair had an effect on her seizures because it was very... it was upright and it couldn't... the angle couldn't really be changed very much. She had a lap belt, a chest strap, a waistcoat and jacket, she had knee blocks and then obviously straps were... and we think it was quite... she didn't like going in it because she couldn't really move and that was really why she changed her school chair, she wasn't due to change because she hadn't really outgrown the other one which is when they tend to change them but we thought she was so uncomfortable and she had all this strapping and her tummy was always kind of strapped it and it was quite a snug fit and they wondered if that had a bearing on the seizures but she's still having the seizures.</p>

Situations distressing to the family have led them to make decisions about equipment use; they now have established routines. Elizabeth spends quite a lot of time on the floor at home.

During fieldwork, on a number of occasions I saw Elizabeth on the tilt table, always in assembly. I was interested in Elizabeth's acceptance of the tilt table, although of short duration and restricted to twice-weekly use. This item of postural management Elizabeth appeared to accept as a positive experience. Straps on the tilt table are broad and distribute pressure, preserving the lower limb position and the height adjustable tray not restricting upper limb activity. With this external stability, there was alertness to the events taking place in school assembly.

[Elizabeth] uses that twice a week in assembly and sometimes we'll use it in the classroom but it is quite big and it's quite adult intensive getting her in and out of it. So sometimes, if other children are off we'll make the most of having, you know, less children, more adults and we put her in it, but she loves being in that. She can see more and I think because she is higher we kind of look at her and she likes the eye contact (1Te1:2).

The code 'use of equipment in assembly', appearing insignificant in this first case analysis, was a noteworthy inclusion when it came to the stage of cross case comparisons. Examination of the data for Elizabeth revealed other sources of information to help me understand comfort and discomfort in new ways. As I

compare her to traditional characteristics of the mental pictures I hold of an immobile child unable to move independently, I note Elizabeth has movement and mobility; the immobility for Elizabeth is that imposed by others, dealt with differently in the home and school situations. A perception based on the aesthetics of comfort, and a discomfort caused by movement restriction.

## **Aiden**

### **Box 8.3 Ideas and perspectives evolving from the findings for Aiden**

For a young child he has pronounced secondary neuromuscular difficulties

Aiden's mother and the school staff are very responsive to Aiden's changing behaviours

Unlikely to use adaptive equipment at home

Chair design features influence perception of comfort and discomfort

Discomfort behaviours linked to equipment

Discomfort appears real to all, but can be at ease

School and positioning options child/curriculum driven

Aiden is a child with all the classic markers that would point to him requiring supportive seating. Unlike Elizabeth, Aiden's movements are much more limited, he also has visual disturbance. His therapist explains:

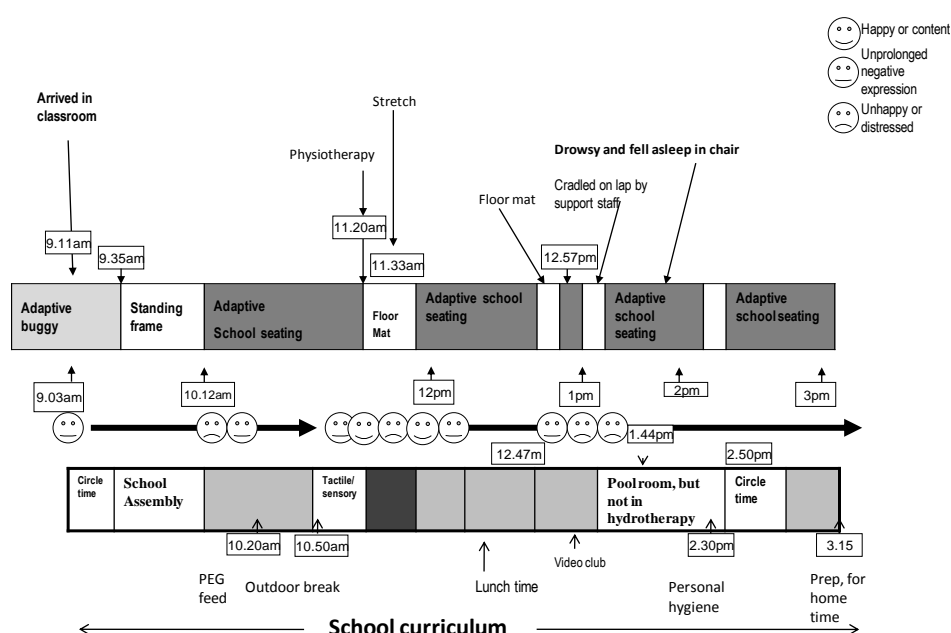
On a good day you get a facial response as if he is listening, his head, he will lift his head up. They are the only sort of responses. They are quite subtle as well unless you know him quite well you might miss that little turn he is actually engaging with you (7Ti1:8).

A small child, small enough to be sat on the lap of caregivers and during the time I spent in the classroom, he was comforted this way by a number of individuals, including teaching assistants, the physiotherapist and the physiotherapy assistant. This human body contact saw him at his happiest, although he was also happy lying on a beanbag, listening to the noise and activity in the classroom.

Close-up video of Aiden's face and the recorded background conversation drew my attention to his awareness of others in his environment. I only saw Aiden display signs of distress on two occasions; both events were recorded in my field notes and there was a video of one. Interestingly both sparked uncertainty as regards the source of distress. On one occasion, Aiden had sat in his adaptive seating for less

than an hour. It was post-lunch break on a cold wet day, and on such occasions, those children using wheelchairs remained indoors supervised by a lunchtime support assistant and one classroom assistant. The children could watch video films; but Aiden appeared unresponsive. I could see his head and upper body begin to display small body movements; the expression on his face was one of grimace. Within a very short space of time, the whimpers became louder and then cries of distress. The classroom assistant lifted him out of his chair and placed him on his side on a floor mat. He then remained on the mat for approximately 10 minutes (Figure 8.2). He was calm and he did not move. Interestingly, there appeared to be expressions, which I interpreted as a smile. He then went back in his chair for two hours in the afternoon with no further signs of distress

Figure 8.2 Observation of Aiden's school day



Below is the transcript of the other field note episode; again, doubt expressed in my own discourse:

Today, the more agitated behaviours occurred whilst Aiden was sitting in his school chair. It would be easy to say that this was due to discomfort. The physiotherapist at one point adjusted his position in the chair and this appeared to give him some relief. This was short lived as five minutes later his behaviour changed yet again; this time he was even more distressed and removed



from the chair by the physiotherapist, who mobilised him into an appropriate postural set on her knee. Before this episode, he received his daily gastrointestinal feed. He was eventually returned to his chair and remained in this throughout lunch and play. He did not display further signs of distress (7FNo2).

Aiden has very limited self-initiated mobility, his leg contractures were immediately observable and his changeable muscle tone seen, if not felt. The observed small facial grimaces I perceived to be an expression of the discomfort he was experiencing during the application of his leg splints, but the gentleness I observed as the teaching support assistant performed this task was inspiring. She was mindful of his needs, and the vulnerability of his emotions. I sensed immediate responsiveness from all the team toward Aiden.

Aiden had experienced additional health difficulties in recent years. Severe pain because of bilateral dislocated hips had marred his enjoyment of school life and mum was in no doubt the cries of distress were unmistakably related to his painful hips. So much so that she gave up trying to position him in a seated position, except for transportation, and unless he was asleep on return from school repositioned immediately on his arrival home. Before surgery, Aiden would cry immediately upon positioning in his chair and then cry all the way to school. School days are long, with a one-hour journey at the beginning and end of each day. As a parent Aiden's mother found it difficult to cope with those cries and would comfort him on her lap or place him on his bed or on the floor, she suggested as much more comfortable. He also has a gastrostomy, so even meals at home are less of a social occasion and mum says it was much easier to feed him on the bed or on a floor mat. The family had to address the needs of a younger sibling which reduced the availability of individual time for Aiden, particularly the beginning of the school day.

Probably three, four mornings, he is upset when he gets to school but he is easily pacified. And I don't know whether his feeds been quick and he has been rushed into the taxi; there are a lot of other elements around that time of the morning and transporting him into school. You know what it is like, there is another little one at home and there may be an element of hurry Aiden doesn't really like, he prefers to be slow he is much better if you are nice and relaxed (7Ti1:5).

Following surgery, all the significant others suggested he was a much happier little boy, smiles and laughs became more frequent, and laughing was an expressive sound that was beginning to return. His mother also linked his happy expressions to removal from his adapted seat. Aiden's mother had memories of her son's discomfort caused by hardware; the straps and fabrication were in her words 'very restrictive' and caused signs of excess pressure

Yet it was a prolonged side lying in bed that led to skin breakdown on his left elbow. She also liked the equipment to look modern and comfortable.

He hasn't really got a comfy chair or anything, where he could just sit and be a bit comfier, he always seems to be strapped and all stuck in and I just think he looks very tight stuck in, and even on his stander he has to be strapped in. I know he has a brand new stander at school. It is a modern one and I haven't actually been to school to see that. He got that a few weeks ago (7Pi1:11).

Varied activities occurred throughout the school day and the teams were particularly good at moving him between the different positions regularly within his class. His class teacher explains:

If I want him to do painting I quite often put him in the wedge and cover the cushion because his hands are down and he can move around because sometimes when he's in his chair, school chair with the tray on his arm are quite restricted because they're all curled up and he pulls them in but when he's in his wedge, because his arms ... I suppose it's a natural position (7Ti1:6)

Aiden's therapist explains that the staffs were very tuned into his needs:

If he is unhappy they usually check if something is not quite right if they haven't got him in [equipment] properly, if he in his standing frame they maybe check he hasn't got pressure on his gastrostomy but if he continues to be upset they will take him out and find a different position for him to play in (7Ti1:7).

One kind of cry is, I'm just simply uncomfortable here, it's not too bad and other children can tolerate it and we can cope and we can change his position and he might still whimper a bit and cry a little bit but we can get on with teaching which is what we're here for but then there's another kind of cry where it is definitely I need to be out and I need to be out now because this is really hurting me and the other children are disturbed by it and we act straightaway and we take him out of whatever he's in ... because sometimes if he's in his wedge or he's in his chair and he's whimpering a bit, he's a bit uncomfortable we don't have to take him out of that piece of equipment we can just kind of rearrange him and straighten him up or shuffle him down a little bit but if it's the other crying it's a definite I'm in pain, get me out of here, take him out straightaway (7Te1:9).

## **Susan**

Susan attends secondary level education. A portrait of Susan, a moulded seat user, was at the forefront of thinking when this study originated. There was evidence of a scoliosis developing at a young age. In mum's words 'that's when the rot set', and at 12 years of age she had to have major reconstructive hip surgery to address yet another secondary health problem, hip dislocation. She was eighteen months when

she went to nursery. She did not have any specialist equipment then and she used to sit in a little square wooden seat most of the time. Mum says ‘there wasn’t a cushion on it at all. It must have been highly uncomfortable and I wouldn’t have liked to have sat on it, myself’.

Susan’s level of sitting ability is fitting with current postural management recommendations (Pountney *et al.*, 2004), sustained head control in sitting remained a challenge. Standing equipment utilized in earlier childhood years was no longer tolerable. In her modified adapted armchair, her moulded wheelchair support, and a similarly adapted school chair the postural position achieved was admirable, and remained so on all the occasions I spent with Susan. She never appeared to be ‘out of position’ and whilst her limited mobility may partially account for this, everyone vigilantly adhered to the meticulous care expected by the family.

With spells out of her adaptive seating for personal care, hydrotherapy and occasional time out on a beanbag at school, most of her 11-hour day she spends sitting. Post-sixteen curricula in school gives emphasis to social life skill development and students often spend time out in the local community. On these days, Susan would be sitting all day. She is of potential high risk with regard to pressure sores, but in mother’s words ‘Yes, I have to say that Susan has never had pressure sores’, although has had very bad plaster sores on her heels.

#### Box 8.4 Ideas and perspectives evolving from the findings for Susan

Susan can appear drowsy, but has alert states. With opportunities for sensory engagement, her responses are subtle

Knowledge of need critical

Meticulous adapted and moulded seating and comfy adaptive armchair chair at home

Sits most of the waking the day. Time out: bean bag, hydrotherapy, personal hygiene

Exceptionally responsive parents-will not see her in a state of distress. Most distressed state rarely equipment discomfort

At school, positioning options are person / curriculum driven.

Whilst the full extent of sensory processing evades assessment, it is the belief that Susan feels pain, but has a high threshold. Other than sensory discomfort arising from bowel discomfort, her Mother says Susan has never indicated any signs of distress related to duration of equipment use:

The only time she would indicate she wasn't happy is, she would be a bit twisty and it would be if she needed changing. She never really indicates that she is uncomfortable in the chair has she? You know I mean the only time she has indicated any discomfort has been to do with needing her pad changing, and if she really is uncomfortable she will whinge (4Pi1:6).

Her parents, and the therapist and teaching assistant who had known Susan for most of her school years spoke about the right arm movements:

She will push you away. If she wants you, if you are there she feels to see if you are there she knows you are there, you chat to her. If you have company, a loud conversation and a laugh, and she makes more noise. A box of mints, metal tins with mints in, we use to have one of those. She would just play with it constantly, in her mouth, chewing. When she has concentration on something, it is intense. When she wants you, she likes to clap her hand and if she comes back to you and turns her hand over, she wants you to do it again. She will take it away because she has had enough, but then a few minutes later she wants you to do it again. (4Pi1:12)

Although blind, her head turned toward sources of possible engagement, but detectable facial expression was often missing during such engagements. The parents, teaching assistant and therapist spoke of smiles, only once during the video was this detected, and the one selected for member checking. During one of my visits to the home (4FNv2) Susan's facial expression changed; her mother was talking about the position of Susan's wrist, whilst moving it at the same time. There was a grimace but no sound and the likely suggestive response to stretch she was applying at the time, a type of discomfort caused by stretch.

In the classroom, there was always noise of one sort or another, background music or interactions between staff and other students. Susan's engagement in these surroundings was not always evident; other pupils were more demanding of staff attention with Susan just appearing to sit on the periphery, her head sometimes dropping forward. Her father said 'Nine times out of ten, she is happy on her own, without fuss, and as suggested by mother 'quite happy to snooze and play'.

During one to one task engagement or a focused attempt by another to communicate with Susan facial expressions were not startlingly different to an uninformed eye, but the video replay did reveal responsiveness in the right upper limb (4v2). There were a number of events interpreted from the video replay, not picked up during the more structured observations.

## Janet

In comparison, Janet has more within chair movement than Susan does. She also attends secondary school. She communicates symbolically and uses some single word utterances.

### Box 8.5 Ideas and perspectives evolving from the findings for Janet

Janet's choice is not to use standing equipment

Stretch causes discomfort

She does move within the chair

Does not use equipment in-doors at home

She objects to other dislikes

It is difficult for Janet's mother to use equipment, which might inflict discomfort or restrict movement

The equipment Janet uses has changed over the years due to a number of secondary musculoskeletal health conditions. Janet's mother and the physiotherapist spoke about the time she could manage short walks using a wheeled walking aid, but due to hip related problems it was eventually abandoned. An item of equipment which changed Janet's life was an indoor powered wheelchair. It appears many people thought she would not be safe, but she surprised everyone including her mum. Used only at school, she is removed if she has an 'off day', where a seizure might be imminent. She is able to take the attendance register to the school office, from her classroom, although sometimes gets distracted in the corridor if she meets meet other students or staff. She just loves social interaction and listening to people's conversations. The physiotherapist still recommends her postural management plan should include standing on the tilt table, but she is certainly not enthusiastic about this and never has been. She does not like the muscle stretch to get the straps fastened. She objects, resists and moans, although once in the upright position she becomes acceptant for short periods. Sometimes they take her down quickly due to the worry of a seizure. Janet has never had any pressure sores, even though she would sit in her wheelchair all day if given the opportunity, but she does have a good quality wheelchair cushion.

Table 8.3 Views about Janet and standing

Teacher	Therapist
Her [Janet] complaints are with the standing. He can become uncooperative if she doesn't want to stand, more noticeable perhaps after the holidays as she hasn't stood for a while and she will, she will become very uncooperative and shouting and .... She doesn't get away with that sort of behaviour and I think she realises there's no point in, you know, a few stern words and she will cooperative and then she will stand very nicely. She never complains once you've got her into position standing, because it's unlikely that Janet would ask to come down, you can tell by looking at her that she's certainly.	She'll [Janet] lie down but the minute you want to strap her down to stand her up that's when she starts to complain because she doesn't want to stand up. I don't think it's totally to being uncomfortable. Just because of knowing her all these years I know if it was uncomfortable I would get a different reaction.

Janet may not always sit the way a therapist might want to her sit, but on request she will make some postural adjustments:

Yes, she does fidget. I presume she must be just readjusting herself. She's never sort of said that it's uncomfortable or hurts, she just does it, and you can see her have a bit shuffle. I don't know that it's ever been uncomfortable but it may be and she just needs to have the need to move (6Ti1:14).

She likes to be part of a group and likes attention. This need for interaction has more than a social element; she sometimes gets into trouble for turning around in her chair to see what is going on behind, instead of concentrating on the task. Nonetheless, on a positive note the in-chair movements might give some relief.

## Vikki

### Box 8.6 Ideas and perspectives evolving from the findings for Vikki

Equipment has resulted in a pressure sore in the past
Vikki uses an adapted armchair, likes to spend time on floor at home
The behavioural change when Vikki was placed in the supportive walking frame was astonishing.
Vikki's parents are vigilant and provide meticulous care. Her mother trial tests for comfort
Behaviours can be subtle, but identifiable for those with knowledge
Planned person centred care planning governs postural repositioning

Vikki attended the same secondary school as the other young people in the study, but now goes daily to a day centre for people with learning difficulties. The children and young people in this study come into a high-risk category in regard of pressure sore development; inclusion of Vikki reminds us of an ongoing vulnerability when vigilance eases. Vikki developed a pressure sore, which I labelled as one of the situational events; the process of elimination to identify the source of Vikki's distress told me something about the discomfort she was experiencing.

When I first met Vikki, her bright eyes drew my attention. There was expression but sparing interactive engagement, even in the presence of those closest to her. She looked, but not appearing to see. Nonetheless, smiles and an occasional out-loud laugh were the expressions which gave those closest to Vikki a reassuring sense that she was content. This was important for those with caring responsibilities. There was contentment; a period of observation, which included a lengthy one to one day centre activity, produced little change in my field note recordings 'no lower limb movement, no change of facial expression, perseverant upper limb movement'.

Nevertheless, what was the extent of her emotional repertoire? There was more than contentment; there was a huge display of happiness and enjoyment on transfer to a supportive walking aid. This was unexpected. She had freedom, she had movement; the transition was remarkable. This assistive device had only become available to Vikki following transfer to the day centre; her final years at school saw increasing periods spent in the sitting position. She did not take a great deal of weight through her legs in this device, the components of the walking frame supporting, yet she managed to make the device mobile and could cover substantial distances in the large recreation hall rarely blocking herself into corners. The sitting position was unavoidable for Vikki, as was the need for additional support not provided by a conventional wheelchair. Vikki's health condition was expected to deteriorate, but with the support of her parents was able to go through major surgery during her teenage years. The surgical procedure helped stabilize her collapsing spine. Vikki was high risk but remained free from pressure sores until an event changed this status quo, making her immobility in sitting more apparent. A new supportive mobility cruiser had insufficient spinal contouring and pressure relief facility and an open pressure area attributed to prolonged sitting the consequence. A revised care plan involving equipment revision was necessary as Vikki was still at school at the time. Intuition had lead Vikki's mother to an explanation for her unusual unhappiness and negative facial expressions. The experiential pressure

sore incident triggered change and more frequent repositioning at school. This was sustainable on transfer to adult services.

Those who describe extreme expressions were able to do so because they felt Vikki was generally such a happy person and identification of distress was not difficult. Finding the cause of the distress was a challenge even for those who knew her well. I only saw Vikki distressed on one occasion, it was in the dining room at lunch time. Her main key worker explained this to be related to the delay in receiving a portion of birthday cake that was been distributed to the other service users on that day. Mother related this to the high noise levels in the dining room. A process of elimination was the strategy used to identify the source of distress; both looked for contextual clues. Whether the distress related to sitting discomfort was yet another challenge, but on that occasion Vikki had spent time out of her chair on the morning of this event. Vikki's mother explains:

She definitely has different sounds, it's amazing the different sounds she makes, and you know it really is. She'll either rub her eyes, mostly rubbing her eyes and rubbing her nose, that's when she's uncomfortable and she wants to be out. And you can tell because she moves around more. She will move her back like that or you'll see her go like that (demonstration). She's not as much moving her bum or sometimes she does do that. She'll rock, well not rock, she sort of like, you can see a move, she cannot get far, but she'll move just a little, sort of like wriggling a little bit. Not so much moving right forward, it's like moving as if she's uncomfortable, and if her legs are hanging, she can't move her legs, she can't get them back on the footplate (12Pi1:27).

Home is a welcoming environment for Vikki; the family believe home is 'her time', an environment without demands or expectations and where she is free from straps. She has in the words of Mum 'a comfortable supportive arm chair', which Vikki's mother has sat in, as she has all her items of equipment. Mum knows what she wants for her daughter in terms of comfort.

### **Ellie, Hannah, Brendan, Peter, Nicola Stephen and Phillip**

In this section I use data extractions from the different levels and forms to illuminate case detail. Direct quotations from the family, the therapists and school staff form the greater part of each display but I embed within each a vignette, which offers an interpretive perspective as I try to frame impressions about comfort/discomfort.



## Box 8.7: Ellie

### The classroom teacher to the researcher

She is really smiley isn't she, she does laugh at things as well. You definitely know when she is not happy

Her facial expressions, she will cry for one and her twisting of her face she lashes out a bit. She gets stiff and she becomes agitated. It's as if she is trying to get out, do you know what I mean, and it's as if she is wriggling

She will stiffen if you put her in the chair, if she has been in the sensory room or something like that, that she's enjoyed

I think once she's in her chair she's happy, for oh its dinner time now she's always fine or if we are doing activities on the table with her. I think she does, fine. It's hard to associate relaxed with Ellie because she is so rigid, you know

She is not so keen on the corner seat and the stander because her legs go into the gaiters then and I don't think she likes the gaiters.

### About Ellie

Ellie's classroom is visual and appealing, she looks content in this environment, more so with interactional /sensory motor activities. Ellie is not yet using a communication tool, but there is alertness in her facial expressions. Her chair adjusts so she can be at the same level with other children in her class; she appears happy and smiles when this happens. Ellie has some control of her mobility when placed on the floor; she doesn't roll over or push up on her hands or forearms, but appears so content with the freedom of movement she is given in the multisensory room. She traverses the small room squirming and wriggling across a room on her back. In school she copes with all the positioning equipment as long as she is occupied as she can use her hands to crudely to manipulate a toy placed in front of her on a tray or table, although she still tries to swipe and grasp toys when sat in less posturally supported positions.

### Ellie's mother to the researcher

Initially I just didn't like the look of it. I didn't want my child in something that was different to what any other child had, you don't want them to stand out and be different. It looks like a torture chair. She absolutely ... even when she seen you put pull it out she would go hysterical. Eventually we got her a bit more used to it when she realised she could do things, not herself but more freely when she was in it because she was sitting upright and she could play on the table top of it but she hated being in it, absolutely hated it. I mean you could put her in and sit her in front of the telly and she would watch the telly but that wouldn't last long. Her concentration is not great so the need to entertain while she was in the chair was there. You couldn't just sort of stick her there and think oh well she's sat in the seat, she would be quite happy, that just didn't work.

I mean she still did the twisting of every child that they're bored or she couldn't pick something that maybe she dropped. She still needed entertaining when she was on the floor but not as much as when she was in her seat.

### Ellie's therapist to the researcher

Full of smiles, when she is not engaged she closes her eyes. She will start to rock side to side if she wants to be out. Moving around on her back is something she enjoys. I think it is her mode of movement at the moment, because she can do it, she does do it. For standing, and use of the corner seat she does register that it's uncomfortable but we need to stretch her hamstrings She soon forgets about it and gets distracted with something else.

### Researcher's journal

Ellie is young at present, but does appear very interested in her surroundings. She appears to enjoy the school environment. The school staff utilise all items of equipment. The standing frame was used in assembly, and whilst I could detect a grimace during the application of the gaiters once Ellie was in assembly she was fine. She reached out to her right side on a couple of occasions and I believed she was trying to interact with the other children.

## Box 8.8: All About Hannah

<p><b>About Hannah</b></p> <p>Hannah appears to be a placid contented child; she smiles and waves her arms. Hannah uses her hands to mouth and to explore almost everything, which is why she likes to be on the floor as this gives her freedom to move to move independently. She rolls, wriggles and bottom shuffles. In her adapted seat she wriggles, rocks side to side and will reach and pull on objects placed on either side if more desirable than the selected tray or table activity. She prefers to have her hips and knees flexed up onto the seat, although her movements are not restricted. She loves food and will tolerate any position and item of equipment if she is fed. At school, she often stands for cookery as the tray has a bowl so she can finger the ingredients.</p>	<p><b>Hannah's classroom support worker to the researcher</b></p> <p><i>If it is bad temper and it is something she doesn't want to do and you stop her and tell her very sharply, she will stop, she might start again but she will stop and if it was pain or distress, it would make no difference. So if it is paddy you can distract her, but if it is pain or distress you don't, it go on an awful long time, because she can't tell you</i></p> <p><i>But I would say 50 %; she would be in her chair. She loves being on the floor, so obviously that is her preferred choice. She'll not object to being in her chair, but I would say on the floor</i></p> <p><i>No, except if she was in a very bad mood and not very happy and we would put her in another time. If she isn't happy going in she would fight you all the way, she would push back, move her feet, she would be struggling and if you don't feel very well, it is the last thing you want to do anyway, and we wouldn't do that. If we think, it is sheer paddy we would give her a few minutes and then try her again and then you would know that is what it was.</i></p>	<p><b>Hannah's parents to the researcher</b></p> <p><i>School have noticed a massive change in her. Obviously it helps them as well because she's interacting a lot more and as you can hear she's very noisy.</i></p> <p><i>She's been in it quite a bit at school during the day so we just think that, you know, sort of like it's time off when she's at home. Do you know what I mean?</i></p> <p><i>She's nearly always happy. You worry when she's not happy.</i></p> <p><i>She's been in it a couple of times at home but not much</i></p> <p><i>She has got leg splints as well to get her posture correct in the standing frame.</i></p> <p><i>Yeah, her feet are strapped in, I don't like that either. But I think... my opinion, she switches off because she's restricted.</i></p>
<p><b>Hannah's therapist to the researcher</b></p> <p><b>We do fasten her feet down when she is moves, as she tends to wave her legs around. Yes it's not that she really needs that, but you know yourself. Health and safety in school, we have to be so careful.</b></p> <p><b>She can box stool sit, yes but she is not safe. She flings herself backwards because she hasn't...because I think she actually initiates that movement, she likes that backward movement. In class she's got a standing frame, she tends to fling herself backwards and we have modification on that.</b></p>		
<p><b>Researcher's field notes</b></p> <p>I noticed the standing frame in the porch. Hannah was happy in this environment. She has floor mobility, she rocks in sitting. One of the main messages to come from this interview was the parental perceived need for Hannah's movements to be free from restriction. They rarely use equipment at home, and keep restriction to a minimum in her outdoor buggy.</p>		

Box 8.9: Brendan

**About Brendan**

Brendan is happy to use his adaptive seating in class and will use his standing frame in assembly providing he is not forgotten about. He likes to be doing, watching and listening and does not like to be separated from his class peer. Everyone does not get him into the equipment correctly. He make this known; he moans and groans and if not readjusted will scream. This discomfort appears worse if he is not positioned correctly for his feed. He appears to have an intense dislike of long leg sitting with leg gaiters.

**Researcher's journal**

Fluctuating high tone, dystonic, asymmetrical Brendan is not currently using a communication device, words or gestures, but there is determination and motivation in his behaviours. He seeks out social interaction, makes needs known.

**Brendan's mother to the researcher**

I have had to start using his chair more at home as he is getting heavy and it is difficult to lift him off the floor.

He will now watch videos in his chair.

Brendan cried a lot and I got into the habit of picking him up as he responded to cuddles and I couldn't leave him to cry.

Brendan has a standing frame at home and uses this at the weekend. Everything is a rush during the week.

**Brendan's therapist to the researcher**

He would probably stand for about 45 minutes if he was engaged in something yes, there is no physical reason why he can't stand that long because he actually tolerates it, he has no problems with blood pressure, no problems with pressure from his splints or equipment. It is just as long as he is engaged in the activity. Sometimes he goes out on the play ground standing. Yes if he is in his seat properly, he will tolerate it, if he has not been put in properly and his bottom is not right back and his pelvis is forward then he will not tolerate it past about 20 minutes and he will start to shout and he will moan and groan until somebody comes to sort him out.

I am sure there are ways to give him a voice as he desperately wants to communicate.

Brendan gets board very quickly if he is not stimulated he get fed up and then he will start to whinge and cry and will then try and make something happen.

Very tolerant, he loves to be part of the group, so if the group are all in cookery he likes to be part, be in the mixing bowl, he likes to be part of the group and if the position enable that he is very happy. If he is stood up out the way and everybody else is around the table he won't be happy, and this year he is in with the crowd and he likes to be part of his peer group.

**Brendan's teacher to the researcher**

Like at assembly time he is always in his standing frame, quite often in an afternoon we will wedge him or corner seat him, but it is quite difficult it depends on what we are doing.

I just don't like him being segregated because he loves being with the other kids. He is a social little boy. He likes to join in and if he I stuck in a wedge, it is very limited, he can probably work with one other child but if you are doing a group situation it is very difficult I think he just sees his gaiters and he doesn't want them on.

He would tense up; going in the standing frame he would tense up. It would be very difficult to handle him, it would be 2-man job, it is anyway, but more so, because he arches and he tenses his muscles and it makes it very difficult to handle him that would be going into his standing frame and sometimes he just does that to have you on.

**Peter's therapist to the researcher**

*He has got quite good covering, he is not a skinny child, so he doesn't get the pressure problems, The main problem of being in the chair all the time is his hamstring tightening That is a major problem and we have to get that stretched on a regular basis in school because that does cause problems. He also uses it as an avoidance tactic as well; he knows very well that if he goes down that line we will have to investigate and sometimes if he doesn't want to do something he will moan a bit. Urhhhhhhh, he points and then if you say, is it you leg? He will try to say leg, his speech is quite indistinct, but he is trying very hard and he will always moan then once you've got him strapped he's okay .But, if he is uncomfortable he would tell us.*

**Peter's mother to the researcher**

Yes, he spends practically the entire time sitting.

When we get uncomfortable we move. He does a bit, but I don't know whether it's because he is uncomfortable and moves to get himself a little bit more comfortable. But he has flattened the cushion with sitting on

**About Peter**

Peter can self propel his wheelchair with one arm. He doesn't always go in a straight line, and sometimes grasps hold of furniture. He is almost always happy and likes to be part of his class group. His hamstrings are tight, and he grimaces during application of gaiter splints to allow tilt table use. During this procedure, the teaching supports assistants make a fuss and distract his attention; this he enjoys. However, he does appear happier when the whole procedure is finished and he can go back in his wheelchair. He gives a distressing moan on release of the straps. Although falling to one side in his chair, he reaches and weight shifts. At home, Peter sits in the corner of the sofa, and occasionally bottom shuffles.

**The classroom support worker to the researcher**

*Yes, the standing frame can't move around, when he's upright you have to lie him down to move it around. But I mean it's good for him in assembly, we put him in for assembly because he's standing and I think, he can see everything.*

*Mind, as it comes to the end, yeah, but I mean if he's singing and what not, so if his mind's elsewhere then ..... no he does tolerate it better I think when he's in assembly. I think he's very much a people person is Peter and he does like to be around people.*

*I mean he doesn't get distressed, you know, to go to the standing frame, it's not that ..... he prefers to come out of it but I mean if we say you're going into the standing frame he doesn't get upset, you know, it's just part of his life and what we tend to do with him because he does come to the after school club and of a night time we sit him on the floor because he loves watch the TV*

**Researcher's journal**

Everyone loves Peter. He thrives on inclusion, and seeks out one to one whenever possible .His facial expressions were easy to interpret, huge smiles, bright eyes. On the day of the home interview, using a pointing gesture he beckoned me to sit next to him on the sofa. His legs were crossed. Throughout the interview he remained content. At one point he made an obvious postural change as it to relieve pressure. As school Peter moved the chair, and he moved within the chair He moved his trunk within his base of support, and outside his base of support. He used the movement of his legs to push himself away from furniture and into the direction of choice.

## Box 8.11: Nicola

### About Nicola

Everyone appears to appreciate the discomfort Nicola might be experiencing from equipment; she looks frail and appeared fatigued when she arrived in school, her head rising and dropping as she tried to interact with empathetic classroom support staff. Last year she lost a lot of weight. This meant the tissues over her bony prominences became at risk of breakdown due to a very asymmetrical postural sitting position, the consequence of musculoskeletal tissue changes occurring over a number of years. She currently has some protective padding on her elbow. At home and school Nicola spends a lot of time out of her equipment as parents and staff appear very responsive to Nicola's preferences. Nicola can smile and laugh, she listens to conversations, and she likes to be with people. Classroom peers also appear tuned into Nicola's needs for comfort. She has a very close relationship with the classroom support staff.

### Nicola's mother to the researcher

*...and she sticks her tongue out for no*

*The most comfortable position is when she is lying down*

*If she's just come in from school, she'll want, she'll have a lie down*

*M's problem is she puts her head down a lot, no matter what she'll try and flop her head out of position and we've tried all sorts of different headrests and it's still not doing the trick*

*That's how she looks around really like that; she seems to look around way rather than with her head up.*

### The classroom support worker to the researcher

*She was a bit fragile when she first came into class and we were probably a bit nervous. I did look at Nicola as being very delicate, Confidence builds on getting to know her, you realize she is really quite, no very robust, but that takes time to get to know her.*

*Her yes, no response is very definite.*

*So by sticking her tongue out she lets you know she doesn't want something And, if she's saying yes. She's always got a smile Head comes up more. Those are all the things that increase your confidence, working with her I think the thing I felt happier about is knowing how definite that response was and you learn very quickly that by giving her choices. She was letting us know*

*We did need Nicola to know that she could trust us.*

### Researcher's journal

*When I arrived Nicola was lying on the sofa as previous occasion. This position on the sofa was changed very soon. Mum suggested a degree of discomfort, or the winging was possibly due to mum sitting on the sofa and Nicola wanting cuddles from her mam. Nicola is a very frail young person with obvious severe asymmetries of pelvis, and spine. Her left hip even through clothes appears to be very prominent. Mum tuned into Nicola's discomfort states. Yet another mum who believed their child was very tired after school, and hence needed to remove her brace/jacket, footwear and simply let her relax. A new adapted chair(armchair) arrived for Nicola yesterday. It was in the corner of the room. Mum said Nicola was not impressed.*

### Nicola's therapist to the researcher

*I made the decision probably 2½ years ago to take the bottom brace off because she was so unhappy we thought we'd try and sit her in such a way that we could support her without the brace but we couldn't, She smiles and she keeps her head up and she'll make noises. She'll actually project her voice. She'll shout at you and giggle.*

*Sometimes when she's really unhappy the only way to pacify her is to sit her on your knee and give her a cuddle because she is ... she likes that as well. Sometimes if she's just not ... if she's just being a typical teenager and she's really miserable all she wants is someone to sit and give her a cuddle. She loves cuddles.*

## Box 8.12: Stephen

### Stephen's parents to the researcher

*We would never use the straps we would never restrain Stephen.*

*The waist one, but we don't like to restrain Stephen in any shape or form unless it is absolutely vital.*

*But we now just wedge him in the corner of the sofa. He will sit but not for too long, as long as he is interested in what he is eating, but I believe he goes into his chair to the dining room at school.*

*He falls over even the smallest things, things like rugs and that are quite dangerous because he will trip over them but because he has, possibly linked to his neurological problems such a high threshold for pain, he rarely expresses pain, in terms of crying and usually he expresses his pain if he has fallen over, we have heard the thud, we haven't actually seen it and by the time we get to him he usually expresses it as a frightened rabbit look on his face. Usually quivering, but often very little noise..*

### About Stephen

Stephen can walk, although he does need a helmet and an assistant for safety. He always wants to be on his feet, and is happiest if he is allowed to wander in a safe environment. His home is adapted to allow this freedom but keep him safe as he bumps or walks into barriers. In school they allow this freedom, but for group curriculum activities or individual sensorimotor sessions he has an adapted chair. He can and will sit, but without support not safely. He gets agitated when stationary and restricted. He loves being pushed outdoors in a buggy with his feet and legs up on the seat. Occasional eye contact is possible. Stephen doesn't pick objects and toys up, but if he given one would handle it then drop it. He appears to have some awareness of routines.

### Classroom teacher to the researcher

*When he looks he would be given good eye contact, he sometimes might vocalize, not consistently, occasionally.*

*I think at that point you know he needs to be moved to a different situation, to a different context*

*I just don't think his chair hurts him I just don't think it is what he would chose I think he would probably chose something soft and squelchy that he could squelch up into.- it's the child he is. Obviously at school it is impossible to do that all the time.*

*I honestly don't think Stephen ever... he doesn't shriek, he doesn't shout. He just becomes very, very passive, more passive, he doesn't reach out. He tries to go to sleep.*

*He has his legs up in the buggy when he is out and about. If he could he would lift them .He likes to have his legs up and crossed and when I think about it he can cross them.*

### Stephen's therapist to the researcher

*No, he's not and that's one of the reasons he's got seating at school because we need to be able to give him a safe seat to actually engage him. So he's in a seat that contains him with a tray on so you can actually work one to one because otherwise you would never engage him, you've got to give him, if you like, a workspace He doesn't appear to, he never struggles to get out of it and he doesn't get out of the straps, he sometimes struggles to get out of the chair but it's not ... I think it isn't the straps that are the problem, I think it's just the fact that he's contained and he finds that difficult to accept.*

*On a good day you can get some interaction from him and he'll sit in a circle, he'll sit with the others as part of a peer group which he won't do unless he's into a seat.*

*Wandering around at home, he's always extremely happy, has a nice little smile on his face.*

### Researcher field notes

I think one of the happiest times for Stephen appeared to be home time. There was just something about his facial expression and his response to going home that wasn't apparent at any other time of the day. Throughout the day, there were times when Stephen appeared to visually engage, albeit very fleetingly. Occasionally it was a person, other times an object. He didn't appear to object to the chair, there seemed to be some acceptance. He didn't shout in annoyance or frustration, although he was able to move within the chair. He could bring his legs onto the seat and he could turn within the chair. The right corner of the backrest of the chair was obviously chewed.

## Box 8.13: Phillip

### Phillips's parents to the researcher

*I couldn't say he was madly keen because obviously he had to have the gaiters on.*

*The seating ... apart the corner seat, you know, the moulding seat or whatever, he has no choice, that was it, I'm afraid. Obviously he didn't get distressed or he wouldn't have been in it, I couldn't have done that..The corner seat used to be, I think we used to do about 20 minutes, probably half an hour max, I can't say if he particularly liked it but he was in it for short spells.*

*But then obviously if the equipment gets bigger and bigger and then he moved on from the standing frame to a tilt table, there was no way we could accommodate ... I mean school would have loaned us it during the summer holidays, there's no way could accommodate that here.*

*It's like putting clothes ... I think it will be like putting your clothes on to getting in the wheelchair.*

*You can tell when he's not happy*

*There was no way we were just going to leave him to slump and, you know,... after he started school we had a team of people, friends of friends, we had about 5, pairs of people who used to come and do physio with him every day, some days twice and they were instructed by the physio and all these things definitely paid off but that was something we were so keen, we wanted him to get the best, you know, have the best chance and have the best posture possible.*

### About Phillip

Philip's mother, with advice, has made a lot of choices about equipment and therapy over the years. He once had to use a supportive moulded seating system and a spinal jacket but his seating is now modular and he obtains good pressure relief from a gel cushion that allows him to stay in the seating equipment for 10-12 hours each day if necessary. In his chair Phillip can reach forwards and sideways, and appears to weight shift in his chair. He copes with tilt table standing; his key workers make a fuss and distract his attention but unless interactions continue during use facial grimaces quickly appear. If he is tired at the end of the day he rests on the sofa in the evening, before using a sleep system for positioning during the night. He is an affable young person, but if something hurts or handling is unsatisfactory he will react.

### Phillip's therapist to the researcher

Yes, definitely. He can adjust his own position, yes he does. Obviously he needs to be hoisted for all transfers but what you tend to, you'll hoist him in the chair and you'll say right, Phillip move yourself around and get your bottom ... and he can move himself around and adjust his bottom position which is quite good that he can do that. He feels the stretch and if something stretches a bit too much he does this sort of (pants) and he pushes away from you so then you have to wait and find out where it is if you can but he can indicate with a little bit of work to where it is that is hurting. He tends to sit in his wheelchair quite a lot of the time. Now when he's at the day centre, they have a team meeting in the mornings so he'll go in his tilt table for quite a while. He has a tray on it as well so he'll do activities in standing and then he'll come out of that and go back in his chair again and then in the afternoon or whatever he'll go on the mat or he'll go on a beanbag or he'll go on the wedge which he tolerates quite well and then he'll go back in his chair again. At home, he's in his wheelchair all of the time.

**Phillips's key worker to the researcher** His special gel cushion burst, and he just wasn't comfortable whilst he waited for a replacement He was leaning, his hips were twisted, his leg further forwarded and together . You could physically see he wasn't comfortable because he wriggled. We give him a choice, we use picture cards and say do you want to go on the tilt table or the wedge. He will sometimes pick the wedge...lesser of two evils

### Researcher's journal

On meeting Phillip I was surprised that in the past he'd had a matrix seating, if he needed this as a young child, he has made progress

The day centre staff were eager to demonstrate Phillip's use of the tilt table. Two staff members were engaged in the transfer from his wheelchair onto the table, leg gaiters applied whilst in supine. From his changed facial expression I could sense that he felt the stretch; but the attention and banter during this preparatory stage he obviously enjoyed. With the tilt table upright he happily engaged in a one to one task sorting shapes, but as soon as the adult parted company his attention faded and his trunk more noticeably starting falling to the left.

## **Conclusion**

In this chapter, I have given emphasis to case description and tried to allow the raw data to be explicit and tell the story. Some of the events previously labelled and coded as an 'event' and embedded into the above narratives, for example, Vikki's pressure sore and the frequent need to turn Dominic in bed were immediately recognizable in the data as influential, particularly in regard to understanding discomfort and were broadly in line with my own perception of the physical nature of discomfort.

Whilst it had always been my intention to complete one case before moving onto the next, the logistics often prevented this. On occasion, I had observation data for subsequent children before full thematic analysis of each case. On reflection, this meant I was more open to cross case linkage of categories. This helped me avoid discarding data which might initially have appeared less relevant. To give an example, Aiden's facial grimaces that I observed during splint application linked facial expression to splint application. I was aware from the very early interview with Janet's mother of her current dislike of standing; however, it wasn't until I analysed the different sets of data for Janet did I place more emphasis on the importance of the preparation for equipment use and the contribution of stretch to my interpretation of discomfort. In the next chapter, I illustrate further interpretation using cross case analysis as this enables exemplification of similarities and differences between the cases.



## CHAPTER 9

### CROSS CASE INTERPRETIVE FINDINGS

#### Overview of the chapter

The formal approach to the analysis, the topic of chapter 7, saw the evolution of a thematic case-by-case analysis with the research questions acting as a template for this process. The multiple case selections did not represent a population of cases; I presented the heterogeneity of the target group of children and young people at the outset. Nonetheless, each case provided the opportunity to explore and learn about comfort and discomfort. I singled out a number of categories and implicitly embedded these into the narrative reconstructions in chapter 8, in addition to retaining some source detail of how I came to use each case. The ongoing process of data management led to further refinement based on the connection of patterns in the data and from concepts frequently occurring across categories. To present the findings from this stage of the analysis, I present the re-grouped categories, each as a sub-theme of one main thematic topic area. I link these back to the exploratory research questions in Table 9.1. The intent in this chapter is to retain the individualism of each case, but engage in cross case interpretive analysis.

Table 9.1 Summary of re-grouped categories, themes and research questions

Sub themes	Thematic topics	Research Questions
Responsiveness to internal and external events Behavioural expressions: facial, vocal, bodily Communicative interactions	The experience belongs to the child or young person: uncertainty but accessible	How does the child or young person exhibit the experience allied to positional comfort or discomfort?
Classroom routines Family routines Home is home Knowing the child/young person Parenting and attentive care giving relationships	The contribution of others to the experience	How do others who are part of the social life world of the child /young person interpret comfort and discomfort?
Restriction Passive stretch Positioning errors Duration Avoidance Postural Management Postural Repositioning Movement	Understanding the situational clues	What are the antecedent factors of comfort and discomfort?  How do these relate to duration of equipment use?
Functionality and ease Relief Distraction	Consequences	How does equipment affect understanding of comfort and discomfort?

The first section illustrates the visible responsiveness of the thirteen children and young people, interpreted by others in the form of behaviours and expressions. The experience, however, always remains with the child or young person. The significant others in this research influenced the children or young people's experience of equipment use, and precedent is given to these findings in the second section. Adaptive equipment triggers behaviour and expression, but differential confirmation warrants use of contextual clues, the third topic theme. This theme develops in the fourth section where focus becomes the consequence of actions to manage the antecedents of comfort and discomfort. The chapter concludes with a summary of the main findings.

### **The experience belongs to the child or young person**

Faced with many uncertainties an appreciation of how each child or young person adapts on a daily basis, whether this be to an inanimate piece of equipment, an adult, a peer or any other internal and external stimuli, appears important to this interpretative study of equipment experience. Non-verbal behaviours of the children and young people were visible, accessible, sometimes subtle, and across the cases diverse. Nonetheless, observed signs, behavioural expressions and communicative interactive processes were meaningful, often challenging, to others but important to subsequent interpretation of equipment comfort or discomfort.

#### ***Responses to bodily events, the external and socio-communicative environment***

The children and young people in the study all had unique characteristics, but notwithstanding the variable sensory, motor and learning difficulties all demonstrated change in the manner of engagement with their immediate environment, including Aiden and Susan, known to have a visual impairment. In addition to being severely restricted in their mobility and participation, those with the most profound learning difficulties were severely limited in their ability to understand or comply with requests and orienting arousal<sup>5</sup> was not present all of the time in all of the children and young people. During the daytime hours, Susan, Dominic and Stephen occasionally drifted into a sleep state, often appearing drowsy. Dominic's physiotherapist explains:

Some days, if you put him prone he will just fall asleep. I think [the occupational therapist] is hoping to show us how we arouse him a little more out of that, which we do but even in hydrotherapy, at

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<sup>5</sup>Orienting arousal: increased awareness and potential to respond to environmental stimuli

times, he is sometimes asleep. He quite enjoys hydro, we don't get quite a lot of movement, and we don't get any gross movement. You can make him move a little, fine motor very poor immature hands. He is placing his hands in his mouth all the time so he is self-stimulating that way (10Ti1:2)

Whilst demonstrating change was less visible and more irregular, in comparison to the responsiveness of the other children and young people, both did however demonstrate changeable responsiveness. I questioned Dominic's mother who clearly interpreted her son's changeable states of alertness

Mother: after school he comes home, he has got the option of the beanbag, the floor.

Int: where do you think he is actually happiest?

Mother: if he's awake and alert, in his chair (10Pi1:8).

The teaching assistant also notices Dominic's alertness, she said:

...he does seem quite alert when he is standing up, you know he does look around more I think it's because his position is upright, I think a lot of the time he is in his chair he slouches forward a lot, his head drops, whereas when he is in a standing frame I don't think he can do that as much and it keeps him up, his head up (10Tai1:7).

The video transcriptions also reveal notable events for those individuals for whom orienting arousal did not come easily. I interpreted the following as clear responsive acts, first to the sensory stimulation from the compost and water, and then to the social presence of another person.

Context classroom: environmental science. The others students were potting seedlings at a table. Susan's class teacher places a bowl of water and compost on her lap, takes hold of her arm and places it in the bowl. Susan fingers the mixture, lifts hand out then places it back into the bowl several times. This was a clear responsive act (4v22).

Context classroom: Susan's wheelchair pushed toward centre tables by teaching assistant in preparation for group work. Another student is walked to the circle, and sat down on a classroom chair next to Susan. With her right arm, Susan feels the wheel of the wheelchair and appears to seek contact with peer (4v3).

There may be explanations for the drowsiness; Hannah's therapist explains

...when she first came to school she was on quite a lot of medication, she was very floppy, very disinterested in everything. Gradually, over the year her medication has decreased, she is much more alert, much more interactive (2Ti1:1).

The class teachers had to cope with these changing, often unpredictable and shortened states of alertness. Stephen's teacher says that sometimes 'he is extremely passive and he just seems as though he wants to curl up and bring his legs up and that's the way it is from day to day' (8Tei1:4).

Stereotypical hand movements made Vikki's hands non-functional, which prevented engagement with table activities. Her expressions were omissible of social engagement, but placed in a supportive walking device and allowed to move freely within the environment behavioural change as recorded on video was impressive (12v2). Vikki's key worker reports, 'she's brilliant and she's just got such a different lease of life, her independence, her interactions with other people and the days that you put her in it and she'll just wander around herself' (12KW1:2).

All of the remaining children and young people were awake, alert and responsive, albeit with some variability, to external environmental stimulation during the daytime hours, sometimes irrespective of positioning. These responses appeared more frequent when adults were in close proximity. Ellie, for example, was more demonstrative in regards social engagement

She does love to be at the table with the other children, because the chair goes down, she loves it .She loves circle time as well, if you can get her to put her name on the board, cause you can take her there with the chair lowered, it is excellent. She does smile and she does enjoy being part of the group. Things like painting, snack time, you would have to have her in the chair, she is determined to do things her arms are lashing out, she really tries to grasp things, pull paintbrush off the table, and she will just try to grasp them, just because she wants to be involved (9Tai1:12).

Peter, Janet and Phillip, in comparison to others, were the three individuals in the study who had a greater degree of in-seat mobility and often initiated interactive episodes in response to motivating influences within their socio-communicative environment. All three thrived and sought adult attention, Janet's mother describes her daughter:

Music, she is music mad. Second to music, talking, she will talk for England. She just wants to repeat, repeat, repeat, the same thing all the time. As long as she has someone with her, an adult person, she is happy. I have to say she is happiest at home, she likes school (6Pi1:13).

In addition to the environmental influences, the body itself is subject to internal physiological events. The significant others described outward signs and attributed these to internal processes, albeit with detection difficulties, but becoming the

subject of contemplative thought as they tried to make an informed decision.

Brendan's teacher:

I think it is quite hard to distinguish because I think, is it whether he is poorly or got a pain or whether he is uncomfortable or whether he is just been a little bit naughty for want of a better word. It is sometimes quite hard, and it takes a long time to get to know him and I think even now it is hard to distinguish between them (13Til:13).

One internal bodily state, which was frequently perceived to cause discomfort was the flatus that builds up in the stomach and intestines while food is being digested, often referred to as 'wind' by the participants. Alongside constipation, this chronic discomfort often perplexed the decision making of others when faced with the child or young person in distress.

The significant others also spoke about past pain events, a common feature in the data. Pain, with a cause more easily identified, for example, from a botulinum injection. Alternatively, causation was attributed to the consequence of unidentified pathophysiology within the body, which often called for other health checks to validate interpretation. Pain incites bodily processes into responsive action, and it was the ongoing intensity and prolonged duration of the emotional behavioural responses, which aided identification of acute pain episodes. Ellie's mother describes:

We ended up one night she was hysterical, we couldn't sooth her, she couldn't get to sleep and when she went to sleep she was flitching and jumping and it got to about 3 o'clock in the morning and we ended up taking her to hospital and they said she had such a blockage, they'd never seen a blockage like that in a 3 year old before and the pain, you could see she was in pain, pain, the expressions, the clinging to you as if to say you've got to do something because she obviously can't tell us what it is. So yes, you can tell the difference between discomforts in the seating to pain, pain. She's very good at showing the difference (9Pi1:21).

In summary, people, motivational environments, temporal, somatic, visceral or neural bodily processes contributed to the outward visible signs displayed by the children and young people. The responsive signs were affective, but in isolation lacked the specificity to aid causation identification. Responsive styles and categories of behavioural expression did however emerge from the findings as having importance in the confirmation of comfort or discomfort states.

### ***Behavioural expressions***

In the interviews I had asked about behaviours suggestive of happiness, contentment, pain and equipment discomfort. Appendix 15 presents a summary of all thirteen cases. The extract from Nicola in Table 9.2 demonstrates some equivalence across the data sources. Facial and vocal expressions were clearly important.

Table 9.2 Behavioural Expressions: Nicola

Nicola	Parent	Teacher	Therapist
Happy	When she is quite happy or she will give a little squeal , a happy squeal and bring her arms and legs up	She laughs. She shouts out. She vocalizes. She might have a little scream, she shouts out, If she is fine, her head will lift up and her eyes will light up, a big smile and then you know it is a yes. we know they she is happy.	She smiles and she keeps her head up and she'll make noises. She'll actually project her voice. She'll shout at you and giggle.
Unhappy	She'll do that sort of twisty sound. If she's uncomfortable she'll do that sort of noise there like a little cry or whimper and that means something's wrong. She still has a pet lip [ a colloquialism that refers to a facial grimace when a child is unhappy], she's always done that and if she's got tears or anything it's a proper cry you know something more serious	Sticking her tongue out she lets you know she doesn't want something.	She'll cry, cry, and cry, real sobbing heart rending cries. Yes, very, very upset. Sobs and intakes of breath, the lot, it a full upset, yeah. She'll nod her head, she'll stick her tongue out

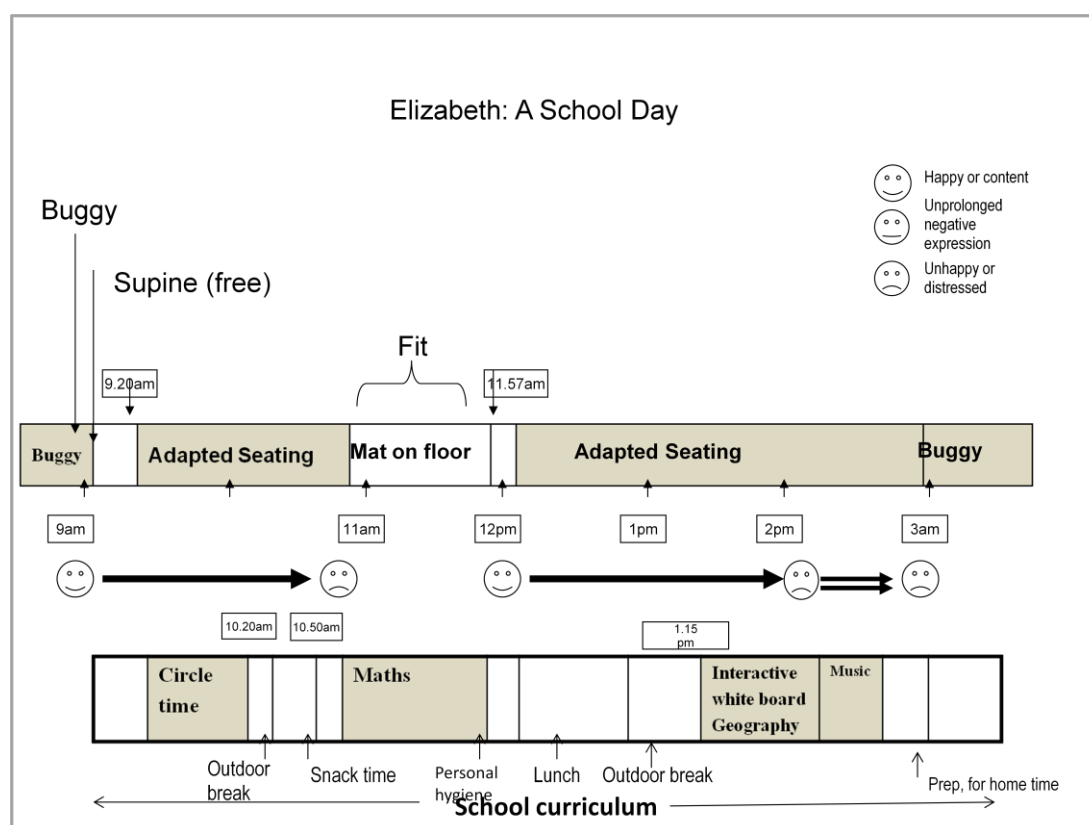
At the end of each interview I ask the respondents to look at a checklist of behaviours extracted from the NCCPC and the PPP. Appendix 19 summarises the data from a separate case on one chart and Appendix 20 summarises all thirteen cases on one chart, listing the behaviours mentioned in the context of discomfort. Again, facial and vocal expressions were prevalent. Sometimes the facial expressions were slight as was the case with Susan, her right arm movement more suggestive of changed emotions. Crucially contributing to further interpretation were the observations and videos. These provided visual records of the behavioural expressions described by the significant others, but also confirm absence of the outermost extremes of these expressions. This finding aided interpretation of comfort.

In seeking differentiation of an adaptive response trigger, particularly those of interest to this study, gradation of behaviour expression was the more frequent mode for interpretation. Again most reported were the facial and vocal expressions. Illustrations of these states were accessible across the data sets. As the significant others completed the list of behaviours they often mentioned that if such behaviour was the extreme it meant there was something even more serious

I knew ... aha, because I mean she was getting upset, it wasn't as though she wasn't, I mean like I said before sometimes Vikki, she can put up with a lot of pain, she just makes like, just mopes around a bit and makes funny faces but this particular time she was actually crying and we had gotten her out and I checked her pads and, you know, checked everything I could think of checking on her really and it wasn't until she was going to bed and I took her things off that I noticed that her back, that her back had been breaking out (12Pi1:15).

During the course of my observations, I observed facial grimaces, but only a few became prolonged. The time of occurrence for the prolonged negativity of expression I identified on the time charts and reported in my field notes. Figure 9.1 provides an example for Elizabeth

Figure 9.1 Elizabeth on use of equipment during one school day



On this occasion, I detected a change in her expressive behaviours following a period of curriculum engagement. At the time, she was in her adapted seat and the changed behaviours were precursor to a subsequent seizure. The significant others took immediate responsive action.

This raises the question; is the presence of a negative state a sign of equipment discomfort? Exploration of this is often difficult without full consideration of context. Elizabeth's seizures were becoming of increasing concern, and as Elizabeth did not like the restriction imposed by her current adaptive seat the team had at one stage considered this a trigger. The team admitted they were puzzled, 'clutching at straws', and the seizures continued even after the equipment was changed. If however it was on one of the days Elizabeth retaliated against positioning, they still held reservations.

Further cross case analysis reveals events where the significant other quite clearly relates the child or young person's distress to a response to the equipment.

I think it is because it is moulded to fit her shape, you have to have her exactly in the exact position or she is uncomfortable. I know a few times she has come back from school and she has been a tiny bit out and she has cried all the way home. I know it's because she hasn't been in it correctly. I can feel the hip bone sticking in the side of the chair rubbing and I know she had been in the wrong position (5Pi1:7).

Yes, because after 10 minutes you can see his face change, he doesn't want to be on it. He is obviously uncomfortable. Obviously, we will stand with Phillip for a certain amount of time doing games and puzzles, but after a period, he does not want to know (11KWi1:6).

I think because they're made out of wood and Ellie could easily get her arms into positions where you don't know how she's gotten her arms into them and she would get them trapped between 2 bits of wood then she would panic, so when she panics she really panics and I think that made her hate the chair even more because it was like horror in her face and I can still see the picture in my head of who she was and I think just put her off even more of being in the chair because she did have good times in the chair, she did laugh and she did play and did do different things then at the bad times when she was like getting stuck or didn't want to be in the chair and I made her, put her off it even more (9Pi1:6).

Other times uncertainty prevails:

If she is uncomfortable, you go through a list. Is she sitting comfortable where she is, is it her bowels? You just have to guess yourself, take her upstairs check her pad (4Pi1:12).



If she's not happy about something, you just go through... you know if she's had her lunch, you know if she's just been changed, see if it's a pressure thing (4Tai1:7).

Subtle in some of the children and young people, and often combined with other clues, but nonetheless negative behavioural expressions suggestive of unhappiness were the clues used to determine acute pain status, emotional distress, bodily discomforts due to positioning errors, constipation, and even fatigue. These were expressions of affect as significant others in close proximity felt the need to respond.

As mentioned, some respondents considered these expressions to contain categorical information, which enabled them to detect not only emotional difference; for example, between happy and unhappy, but the intensity experienced by the child or young person. I probed positioning discomfort and pain states during the interview, the participants often considered discomfort as a gradation of a perceived pain sensation but of a milder nature. Those struggling with interpretation use a process of elimination. The words of the respondents explain the difficulties:

Unless it's obvious, it is difficult. If she had a headache or something for instance I wouldn't really know, she would just be moody or twisty that day really so that's a bit difficult really if she did ever have anything (5Pi1:19).

We usually, oh yeah, we usually can tell with Vikki, the majority of time it's mostly her chest, you know, a chest infection. You know you can usually tell, I mean she's ruttly and you know but like other times she's maybe had a pain in her stomach or bowels you know because sometimes she has problems with her bowels. There was a time when she was really wiggling in her chair, she's practically jumping out of her chair, you know, and we were thinking is it her chair or is it ... and I really think she had cramp. So at that particular time, it wasn't her chair it was cramp that she had, like her period time so, you know, sometimes it is hard to think (1Pi1:30).

I think most people know her clues, yes. Yes, because if she cries and they can't find out what's wrong they'll bring her along and see if I can find out. So they do try all of the usual things like 'Is it here?', 'Is it there?', 'What's the matter?' and if they still can't then they'll bring her along and sometimes they'll check her brace without even asking, they'll just take her out, reposition her brace, put her back in and see if it's been digging under her arms (5Ti1:12).

Sometimes the significant others cast doubt as to whether the equipment was always the cause of more negative behavioural expressions, as the participants described the emotional responsiveness from other factors which might also be a

source of distress. Janet was a young person who could express preference. Her behaviour was described by her teacher:

Her behaviour is the same as if she was asked to do something in the classroom like stop touching something and she didn't want to do that, so it would be very difficult to link it directly to discomfort or whatever, I'm assuming it can't be that comfortable to have the splint on but I think a lot of it depends on her mood and cooperation so it might not necessary be that she is rebelling against going in the standing frame it's being told what to do when she just wants to be left alone and it could be the same if I'd asked her to leave a piece of equipment so could then exhibit exactly the same behaviours, the shouting and complaining (6Te1:3).

In the face of uncertainty, it was those expressive displays of negativity or unhappiness behaviour, in response to distress, discomfort or pain, which prompted the need for action strategies. My field notes also reveal a personal desire to respond to negative events. On the day of Aiden's observation, the weather was poor and this ruled out outdoor play; alongside the other immobile children in school, he joined the DVD group, but was unresponsive to this experience. He was using his adaptive classroom seating at the time. After a short time period, I observed an agitation; he appeared distressed and, like the lunchtime support assistant, I felt a need to respond. The teaching assistant removed Aiden from the seat. There were no clear clues of positioning error.

Expressive signals perceived to represent a disposition toward a negative emotional state appeared linked to aspects of equipment use. These being observed and reported; for example the preparatory passive stretching of musculoskeletal structures did appear to cause distress and was likely uncomfortable or painful for the child or young person.

He is not complaining when he is standing, but one can take him down and release everything, he goes uh uh. You can tell the stretch has been on too long. I try to get it done for an hour maximum (3Tei1:7).

The only other time she's shown any pain was after she had some soft tissue surgery to her left leg, to her left foot and the skin sensation was very severe and she also didn't like the stretching's when we were stretching the soft tissue, but now she's tolerant to most. She just flaps her hand if she doesn't like it and if she really doesn't like it she points a finger at you (4Ti1:2).

I watched them put a splint on and as she stretched those structures you could actually see the expression on her face (4FN).

In the presence of a caregiver, whether the negative emotional expressions were more pronounced could not be determined. This was partly due to the retrospective nature of some of the data and the context of my observations-the children and young people were always close to a caregiver.

### ***Communicative interactions***

The current study did not set out to study the theoretical underpinnings of the interaction patterns between the children, young people and significant others and I gained little insight about their views as potential communicative partners. Whilst significant others and even peers did make inferences based on the contextual clues and their knowledge of the child or young person, these did not appear to be isolated decision making acts of indifference, the school staff gave priority to communication and recognised responsiveness as potentially communicative. Interactive processes were occurring. Elizabeth's teacher:

She'll sometimes turn her head and she'll look around to see, you know, well where is everybody and occasionally she would kind of make noises as if to say 'hello I'm here', you know, 'I'm just here, I don't need anything but I'm just letting you know I'm still here' but not all the time but she's quite happy to ... she just likes looking around, she's quite interested in what's happening and if she's... if it's circle time and all the children are sitting in a circle and she's between 2 other children and it's not really her turn to have a lot of adult input, she's in the circle and she's being supervised but the adult focus is on another child she'll play with the 2 children on either side; she'll giggle at them; she'll smile at them; she'll try and touch them, she knows that they're there, she's aware that they're there and she starts off vivid interaction, just eye contact; giggle; smiles (1Te1:5).

Nine of the thirteen children and young people functioned pre-linguistically, not using symbols in the interactive opportunities that took place within the school learning environment. This did not mean the child or young person would produce a symbolic gesture, but perhaps a pre-intentional awareness of the partner. Yet, the facilitation of communicative interaction was an important curriculum focus. Circle time, which usually took place at the beginning of each school day saw witness to a number of alert episodes during these interactions in those children whose orienting was often erratic and spontaneous. I recorded in my field note observations:

Circle time: the class teacher in turn welcomes each child using a familiar circle time tune in which each child becomes the focus of individual attention. When it was Dominic's turn I noticed a changed expression, it wasn't a smile, but there was an obvious difference of expression. It was brief (10 FNo).

The communicative partner in this instance was the teacher. Dominic's mother also experienced initial hesitancy, but eventually accredited some of his non-verbal behaviours as communicative acts.

Programmes planned with the teams from education allowed an alternative position at some point during the day. There was opportunity to express movement, free from restriction, but adaptive equipment was often adjunctive to the many planned and unplanned environmental incentives witnessed during the day time hours in the schools and day centre, which included: group activities, peer interactions, intensive one to one interactions, one to one curriculum tasks, the use of enticing objects, switches and toys. Hannah has some postural control in sitting, but cannot safely adapt to the micro-environment of a classic classroom chair, she also has some low level floor mobility. They do not deny her this freedom, but at the same time as part of curriculum development class teachers want to enhance her repertoire of social and communicative skills.

I never thought we would know what he wanted or anything but he can tell us know. Yeah, I mean somebody told us you would know when he's uncomfortable, you'll know when he's like not happy and things and I was like well how, he can't tell us, but we have learnt his different whines. There's a whine when he's like bored and there's a whine when he's generally upset and then he has like his proper crying (10Pi1:9).

In the day centre, Vikki's therapist spoke of these interactive processes in times of distress

Especially when usually you can normally tell when she's not happy, you know she's not happy because you're used to her being happy and like interacting with you and just loving what she's doing and then when you see something, oh you're a bit moody. You know you feel somebody language or something, it's very hard to explain but you know when she's not very happy (12Ti1:6).

and Susan's teacher assistant

Sometimes she can be sitting in her chair ..., talking to her, holding her hand and she makes noises back, very much like a 6 month old, making a noise, waiting for a response given, then she feels around your neck, she give you hair a pull. She likes to know what's there (4Tai1:10).

The child or young person's perceived need for comfort was one such topic of interaction Aiden's teacher explains how he lets her know, the interaction led by the child

He kind of moans a bit to start with and his feet move a little bit because he finds it difficult ... he can't really move his legs but he can move his feet, you can see his boots moving a bit as if it say I'm uncomfortable but I can't do it myself, so he lets you know and we change his position (7Tei:14).

Aiden, Ellie and Brendan demonstrated frequent alert responsiveness to these interactions. Susan and Elizabeth's responses were subtle. Dominic, Stephen, Hannah and Vikki responded, but more inconsistently. In comparison, Peter, Janet, Nicola and Phillip sought out the interactions. The teaching assistant in Peter's classroom reports 'So it's usually he will rub and he would call out, he would tell you he'll ow!'. For these individuals there did appear to be some opportunity for negotiation as the conversation with Peter's teaching assistant suggests.

Ta: even when I say "yes I'll do it later", you know, "a bit longer".

So he will keep going on until I do take it off.

Int: when you say "a bit longer" does he accept that.

Ta: yes, but only for about 10 minutes then he'll come back again and say "off", so I just say "right come here and I'll take it off (3Tai1:13).

The classroom teachers have numerous other needs to address each day. Janet's teacher explains the learning process that can be involved in these responsive acts.

I don't think I've ever taken her out without speaking to her or talking about what we're doing and saying 'gosh, I bet that feels better' so I think we're doing a lot of responses for her without really judging (6Tei1:14).

Yes, she doesn't really cry. Yes and I would take that as Elizabeth saying no, I don't want to do it, because I've had her 2 years I've kind ... I'm tuned into when she's compliant; when she wants to do something; when she's unsure I kind of I know that she's unsure because she's not sure what's going to happen and equally I can read all of her signals when she's saying 'no, I don't want to do that', 'I'm not going to do it; and there's no, there's no debate, there's no 'oh perhaps we can something else', 'I just don't want to do it' because she obviously can't tell me that, she can't say 'no, go away, I want to do this instead'(1Tei1:14).

Peter, Phillip, Janet and Nicola could direct the attention of individuals; they often used nonverbal intentional behaviours to indicate their feelings about a particular event or activity. Peter, Phillip and Janet used some single words, and manual signs, such as pointing, in addition to non-verbal vocalisations and facial expressions. The classroom support assistant in Nicola's class describes her behaviours:

Just an unhappy face. An unhappy face I would say and crying, yeah. Sometimes she'll try and shout but it's very rare but if you

look, if you're doing something with her chair and she's not comfortable she may well shout but it's not always, doesn't always come out the volume. So we tend to ask her, you know, 'is this okay?', 'that okay?', 'you comfortable there?' 'does that hurt?' 'does this hurt?' (5Tai1:11).

Phillip's key worker:

We use picture cards; we have a picture of the tilt table, a picture of the wedge. This is the wedge, this is the tilt table, do you want to go on the wedge, and do you want to go on the tilt table. He will choose to go on the wedge in preference to the tilt table, the lesser of two evils (11KW1:5).

Peter, Janet and Philip had some control of their trunk and upper limbs; this is immediately demonstrable in their ability to use the propulsion wheels of a wheelchair, albeit in Peter's case with one arm. In the analysis, the illustrative accounting of communicative function included demonstrative emotions, item experience, activity preference or rejection. A number of the described events could be attributed to the displeasures of some using, but not all, items of equipment. However, even for these symbolic communicators using a pointing or similar gesture, interpretation was not always an easy process, and often still warranted the communication partner to engage in a process of elimination. The ability of the child or young person to indicate some preference was however apparent. Standing was one such activity, accepted but less pleasurable than other activities.

In summary, behaviour states, expressions and interactive processes are taken into consideration, those more negative prompt responsive actions. These behaviours remain relevant to the identification of a discomfort state, whereas absence might have some relevance in the interpretation of an at ease state. Further appreciation of contextual clues extends understandings.

### **The contribution of others to the experience**

Interpretations about the children and young people's comfort or discomfort status were made by the significant others in the research. Their own personal knowledge and the differing contexts where the interpretations originated, in addition to other disparate influences, affected equipment use and positional change. The parents' experience adaptive seating and other items of equipment in the context of family life, and the teachers, therapists and teaching assistants in the context of professional orientation. Curriculum organisation and family routines, the experience of knowing the child or young person and attentive caring were the major categories

to emerge from the analysis, all potentially influencing a desirable at ease state of comfort in regard of equipment use.

### ***Family routines and organisational routines***

At home, school and day centre positional change occurred most often in preparation for specific, but routine events. The families described weekday routines at the beginning and end of each day; there was little opportunity for flexibility because school transport arrived at a set time and invariably the child or young person transferred early into their adapted wheelchair in preparation for their journey to school. Routines evolve around family life. Dominic's mum explains:

When he comes home he'll probably go straight into that chair or they're have like fun time on the floor with his sisters, he'll either go on his bean bag or he'll just lie on the floor and then he's in bed by 7 because he has to have his feed then so it's easy to connect him and put him in bed and he has his lights and his music and everything (10Pi1:2).

Only two families still had a standing device at home and only two used a night-time support. The mothers of Susan, Vikki, Janet and Phillip spoke of equipment used in the past. Size was an issue and a reason suggested why some items could not be accommodated in the home; sometimes a past discomfort event mapped current usage or its discontinuation. However, as a feature of family life, the parents in general were all firm in their beliefs that home was a place of relaxation, a place to be free from the restraints imposed by such equipment. The families were aware of the postural management programmes at school and or day centre; this was therapy. Home was home, and everyone was allowed freedom out of the equipment. Aiden's mother:

Probably take him out of his chair. Lift him on the floor. He has been in a chair all day at school. That journey on the bus home is quite long time-just stuck there squashed in that chair (7Pi1:6).

Janet's mother:

She doesn't sit in the wheelchair at home, apart from going to school. She sits on the floor. The chair; we don't leave her in the wheelchair all day. I don't like it, her legs swell up, cause she's not moving around enough. I prefer her on the floor so she can just move around (6Pi1:7).

Views about home as a haven away from the afflictions of equipment and restrictions were strong. Janet's mother mentions she just wants her daughter to have that freedom and be able to do what every other person does. The therapists were not oblivious to these routines, Aiden's therapist:

In terms of the equipment time wise, he will be in his buggy for about half an hour for transport, he will sit in his school seat for another 45 minutes, and then unless something else happens to him he will be taken out and may be lie prone and then he will go back in his seat for lunch, and then he will come out of his chair for something. Unless he is out on the bus for a full day, then he will spend a little bit longer in his buggy and then when he goes home mum will tend to put him on the settee. I think she tends to use the seat at home mainly for weekends and feeding and then to bed and is lying out in bed so he gets constant changes, but some days he sits longer (7Ti1:1).

In the home, less decision-making situations arose because parents at an earlier point in time had already made the decisions about which items of positioning equipment their son or daughter would use at certain times of the day. Asked about a typical day, families spoke about daily routines, which at the start of each school day inevitably involved a predicted course of events in anticipation of their son or daughter's journey to the school or day centre followed several hours later by his or her return, often in a state of fatigue.

Yes, she comes down here first then has her music in, get her washed, then put her in her wheelchair, push her in the kitchen give her breakfast. Bring her music in and then give her breakfast. She's in the wheelchair ready to go to school (6Pi1:7).

The parents had to use some items of equipment, particularly for transportation, but items more easily abandoned in the home were those making care processes burdensome or causing their son or daughter distress. The routines the families describe reveal more. Nicola had just been issued with a supportive armchair for use at home as she spent much time in a lying position on the sofa. Her mother explains:

Really, the most comfortable position is when she is lying down, but, it is obviously not the most ideal position; that is why she has this chair now and I think that when she comes in from school she wants to get a lie down, her brace off and things. Obviously, I haven't got into a routine yet, but I might put her in the chair for feeding her because she usually is quite tired when she comes in from school (5Pi1:2).

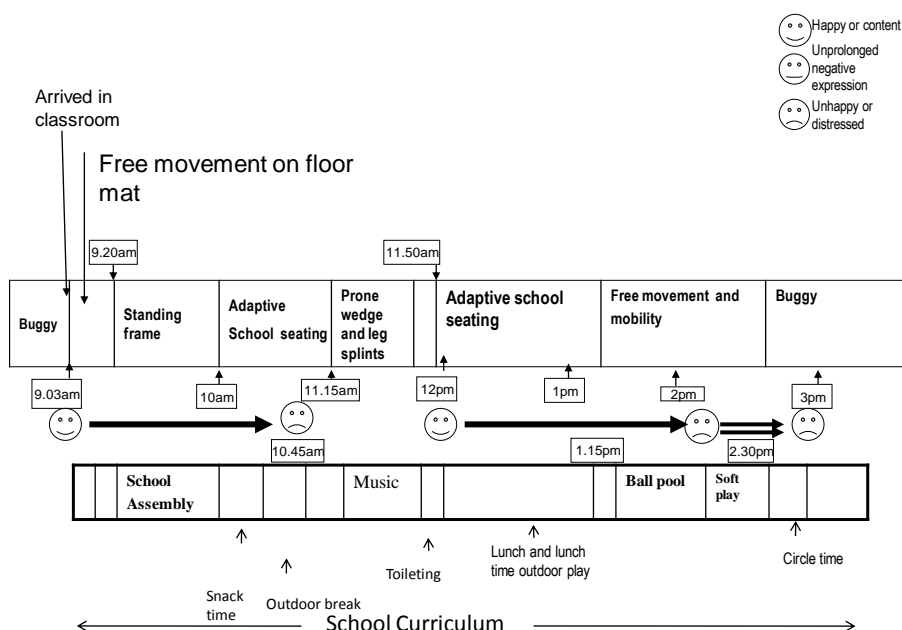
From a therapeutic postural management perspective, the unsupported position on the sofa is less desirable, but the transfer itself clearly facilitates a positional change, which gives the child or young person some relief from a previously adopted position.

The time charts documented in chapter 8 reveal typical days with regard to equipment use at school and at the day centre. Figure 9.2 documents a typical day



for Ellie, one of the young children in transition to school. Inclusive of personal hygiene, Ellie experienced eight transfers and four items of postural management equipment during the school day.

Figure 9.2 Ellie's use of equipment during one school day



The educational teams had to take into account the needs of all pupils or students; the beginning of the school day is a busy period and Elizabeth's teacher describes how on a Friday because she had hydrotherapy at 9.30am, they leave her in the buggy, rather than transferring to her school adapted seat for just half an hour. In special education some pupils function at the earliest level of development, this means educational teams have to take into consideration other needs when planning the curriculum. Lunchtime involves a midday meal or snack, followed by free play, or for the post-sixteen pupil's opportunity to spend time in the social lounge area. Three of the pupils in the study required enteral feeds via a gastrostomy, the others maximum help with feeding. All these events involved the seated position, although on one occasion I observed Hannah spending time lying on a mat in the school quadrangle, as it was a warm, sunny day. Snack time mid-morning also involved the seated position. Other care needs include personal hygiene activity, which requires less time out of the curriculum, an event that does however necessitate a positional change, which may bring temporary relief from restrictions imposed by equipment. Janet's therapist indicated that for at least 20 minutes twice per day Janet would be involved with personal hygiene tasks. Beth,

one of the young people in the preliminary study, spoke about the relief of being in the hoist. The school curriculum varies for all pupils, but in special education, the pupils often access hydrotherapy and multi-sensory rooms alongside the more conventional lessons. Both these afford the opportunity for the child to experience free movement. Pre-planning of highly structured days allow for the positional changes, some postural management, and possible relief from the adoption of one postural position for too long a period.

Advanced planning cannot account for eventual and unexpected situations that inevitably occur, for example staff illness. Nonetheless, in these contexts postural repositioning was the consequence of collaborative practices and the findings reveal the intent to embed postural management changes into the daily curriculum at school, with care packages established within the day centre. These intents can be successful as the teachers reveal:

Yes and every year, the start of year when you get new children you get a risk assessment from the physios and like what kind of positions each child should be getting. So you know at the start of the year what you have to do for different children because they're all different and even though I had Elizabeth in my last year she still does that again so you know at the start of the year what to do. So you're not really getting a new child and thinking, oh I don't know what to do so I won't do anything (7Tei1:3).

There will be times, oh yes without a doubt, I mean depending on our timetable, but we aim to try and stand her 3 days or 3 times a week but with staff absences and all sorts of other things going on it doesn't necessarily always happen. Also when the timetable changes because she's out or doing different things obviously (6Tei1:7).

I think from a teaching point of view I just think that whatever you are doing, in your planning etc you do think about how long the children are sitting, to make sure there are opportunities. I wish we could more. I wish I could say he is out every morning, every afternoon but I can't because I know that is not the case but I can honestly say he is out every day and that is something we can possibly head toward for someone like Stephen or for any of them.. He loves to be out I think it must feel very restricted. Oh yes without doubt and I think staff are very aware; there is lots of support for students to be taken out of chairs to do other activities. People will do that and recognize the importance of it (8Tei:7).

I would say 50 %; she would be in her chair. Yes, any chance we have we would take her out, so if it Friday afternoon or free play, she would be taken out of the chair and placed on the floor, so she can access whatever she wants, she will shuffle along, so she is only in when she needs access the curriculum and in the playground as there are too many children running around to let

her out. We do put the mat out and outside but if everybody is out it is just too busy, other people running around (2Tai1:6).

### ***Knowing the child or young person***

Most of the significant others in the study often found their interpretations tentative, not always knowing whether their judgements describing the experiences of the children and young people were correct. However, when confronted with behavioural expressions deemed more negative in origin observable information required processing more urgently; for example, was there an error of positioning, were the straps too tight or too loose, were the facial expressions and vocal sounds prolonged? In the presence of clues, and prolonged behavioural expressions, the outcome of the situational decision-making was invariably removal of the child from the equipment. The parents, direct support staff and professionals perceived personal and past experiences to be important in the making of on the spot decisions about discomfort. Two of the teaching assistants explain:

His expression, you can tell, you know, the more you get to know him, you know, you know like you can see if he's not too well that day, I think it's just because you know him and you can tell by the impression on his face. I mean he does cry but then he can cry quite easily, you know. I mean I wouldn't take that as a massive indicator because if anybody speaks to him sharply there's a flood of tears or you know, and he doesn't like you to be disappointed in him. You know, he's a lovely little lad but I think it's just because you get to know him that you get to know if he's in discomfort and it always seems to be the same place (3Tai1:7).

She'll bite her hand, she'll bang, she'll be distressed, you can see the way she wriggles, again, it's because you know the child, if you see her happy, she is happy as can be, but it is really no different, if she's distressed with anything else she is doing, it could be an activity she is doing on the floor, if not going well, you get the hand biting, the hand right back in the mouth, throwing, hitting out. It is very clear if Hannah doesn't like something. Hannah also has a paddy and you have to watch (2Tai1:3).

When a negative or unhappy behavioural expression occurs without observable physical factors the reasoning process becomes more complex, but again the outcome of any judgment did appear to contribute to the contextual accumulation of decision maker experience. Over time this gave the significant others confidence

Yeah. I mean somebody told us you would know when he's uncomfortable, you'll know when he's like not happy and things and I was like well how, he can't tell us, but we have learnt his different whines. There's a whine when he's like bored and there's

a whine when he's generally upset and then he has like his proper crying (10Pi1:9).

Recall of past events relating to a discomfort experience was a common inclusion found in the narratives belonging to the parents with instrumental events often accounting for current actions and personal perceptions. For example, decisions to abandon certain items of equipment:

But then obviously if the equipment gets bigger and bigger and then he moved from the standing frame to a tilt table, there was no way we could accommodate. I mean school would have loaned us it during the holidays, but there's no way to accommodate here (11Pi1:5).

Apparent in the explanations offered by the therapists was a perceived emphasis on the importance of therapeutic postural management if avoidance of discomfort was in the long term was to be minimised. However, whilst influenced by their professional orientation there were no overtly expressed paternalistic views by this professional group or rigid adherence to convention. Collaborative working I observed and when it came to equipment use, the therapy team were just as likely to remove the child from the equipment if it was perceived to be causative of discomfort.

With potential to influence both comfort and discomfort, the influences on decision-making processes with regard to equipment use varied. When asked about decision-making strategies relating to equipment use, the teachers spoke about placing emphasis on strategies for supporting functional communication development and increasing social participation. In classrooms, this was an important observation. Equipment use supported these aims, with purpose generally achieved. This suggests the child or young person was not in a distressed state at the time. The educational teams had insight into some of the health care risks. They spoke about contractures and pressure sores working closely with the school therapists to timetable positions other than seating into the school day, although some held personal views about the potential of certain items causing discomfort. Seating was most often the preferred option; the staff in primary school indicated assembly was the best time to use standing equipment, as more space was available in the school hall. I observed this event on several occasions; this was opportunity for distraction for the position perceived by some as less comfortable than sitting. They spoke of successful standing.

### ***Parenting and attentive care giving relationships***

The narratives and observations illustrate the impact a distressed child or young person has on the parents and significant others in this study. Some items of equipment and/or the preparatory techniques did cause some of the children or young people discomfort. For parents the findings give some insight into their emotions when their son or daughter is distressed.

It's hard, it's really hard to see your child so upset knowing that they're telling you it's going to help them in the long run but you don't see any of those good side effects, you don't see them for quite some time to be truthful. So you're being told to persevere, ignore the crying because that's just for... or you know, I'll cry and my mam will stop ... and it was really hard and these equipment's didn't look nice, it looked like torture equipment and you don't want your kids in stuff like that. You know, I mean you could see somebody had spent time and effort making it but it was still horrible and I hated her in it, absolutely hated her being in that (9Pi1:11).

Such emotions may conflict with their needs as parents to protect and provide security for their son or daughter. Dominic's mother said 'I can sleep if he still laughing but I can't when he's whining or crying, I've got to be there'. Age was no barrier and the parents of Vikki and Phillip regularly attend to their needs during the night. Vikki's mother explained that they still go to her about three times a night, usually in response to a groan, but if she herself suddenly wakes she thinks 'Vikki's never moved for a while I've got to turn her', a need, which sometimes, but not exclusively, related to positioning discomfort.

A distressed son or daughter is difficult to ignore. Susan's father said 'being a parent you know the signs straight away, you know something needs to be done'. Dominic's mother is aware that her son gets uncomfortable and has to be turned and repositioned at night; however she also knows he gets bored. But still she can't ignore his distress. She says that sometimes he is just bored:

Yeah because you go in and he'll start laughing again he just wants your there, as soon as you walk out he'll start again and you go back and he just laughs which is great but at 2 o'clock in the morning it's not (10Pi1:9).

Parents did not like to see their son or daughter distressed and over the years had found ways to comfort their son or daughter. The findings gave some insight into coping mechanisms, which did have an impact on equipment usage. The more usual way of comforting the younger children in this study was the security of the parents

lap, but even Nicola now in post-sixteen education was still comforted this way. The sofa or beds, with additional comforting artefacts were the alternative.

The point of response sometimes varied; those with experience of years appeared to read more of the contextual signals and offered interpretations other than equipment discomfort. Janet's mother

Me, yes, and no, because sometimes she can whale for nothing and that is if she is in a mood on the floor. If she is in one of her tantrums she can whale for England, so yes but there again it is a parent thing I would just know when she was poorly, whether it was just a strop, you would know because it would go on and on and she would be really upset, then the whaling would stop and then she would go on crying. There is a slight difference. Her face would change as well and you would just know the crying (6Pi1:5).

Yet responsiveness to distress in the current context was difficult to deny and if the parents perceived their son or daughter to be distressed and equipment considered the source they were proactive in contacting the school. One post-sixteen teaching assistant explained:

No, because I think her mum wouldn't allow it. Her mum would have spoke up. There are children that you know are uncomfortable, you know the wheelchair is not right for them, you know they need bits added or taken away but they are usually the passive parents who just take it (C4Ta1:9).

The significant others involved in the implementation of the postural management strived to fulfil professional aims, and eagerly recalled these in the narratives. Nonetheless, they were aware of the child and young person's likes and dislikes, emphatically sensing certain procedures potentially inflict, rather than alleviate discomfort. The teaching assistant states:

I've took him [Peter] out before if I've thought he was distressed about and if he asks then I think you know I feel that well if he wants to come out then it's got to be hurting him because he does tend to complain about the same leg and. [the physiotherapist] has checked it and she's said, you know, he's fine but if he complains that I have to take him out earlier (3Tei1:4).

He responds really well to being picked up. We can't pick him up too often because he knows that if he cries someone will give him a cuddle and snuggle him in so he cries even more, but he likes to be picked up. He likes to be moved and he responds quite well to that (7Tei1:8).

The video transcriptions reveal this responsive care-giving act. These actions further demonstrate awareness of the child as person, seeing one of the pupils or students in distress often shortened positioning times.

I mean she has come in first thing in the morning she has been quite quiet coming along the corridor and then we get her in here, and she's got really upset and we just have to get her out of her chair straight away. I think it's because, I hope it's because she knows she can trust us knowing how she's feeling if something wasn't right, it could be her hip in her chair. It could be her AFO on her leg or something like that anything. We just try to get her out the chair as quickly as possible (5Tai1:7).

Later stating that 'I couldn't personally leave her for longer than that or tell her it's alright'.

In summary significant, others function within environments, where personal knowledge, attitudes and organisational systems influence individual behaviours In this section, I have revealed a number of person-person interactions, which may affect upon the child, and or young person's experience of equipment use.

### **Understanding the situational clues**

Physical sources appear to trigger explicit interpretation of comfort/discomfort existence and because all the significant others linked some current or past discomforts to items of postural management equipment this section first considers the contextual physical clues from across the data levels and sets, which may be of relevance to an understanding of equipment discomfort. Contrasting and not manifest across all cases, the findings condense into the following categories: restriction, stretch and prolonged stretch, positioning errors, fatigue and duration as causing discomfort. Inherent also in the findings were descriptions of successful equipment use with expose illustrating the potential to achieve an 'at ease' state of comfort; these include avoidance, postural repositioning, postural management and movement. The potential impact of non-physical influences does not evade disclosure and the section closes with exposition of aesthetics.

#### ***Restriction as causing discomfort***

Visually, if the child or young person appeared excessively restricted in the equipment by any of the adjunctive positioning accessories this was a concern for quite a number of the parents. The conversation with Aiden's mother progressed as follows:

Mother: I think a lot of his chairs are quite compact, he is stuck there, a lot of straps and stuff, and some are needed for safety. He will flop forward, but some of them are like a straight jacket  
Int: like a straight jacket  
Mother: yes he looks uncomfortable (7Pi1:5).

More so in children and young people with spontaneous limb movements.  
Ellie's mother:

Fixed, she hates being fixed. Ellie loves to be free, she loves to be able to go where she wants to go and play with or do what she wants to do. She is a very determined child and she would be, if she could be, she would be the most independent child I think I have ever met in my life, but she just hated the straps and being put into that position and stuck in it. I mean even now, on the equipment we have now she's still the same and the equipment now is more padded and it's more comfortable, she still doesn't want to be in them (6Pi1:9).

Hannah's father:

When she has the five point harness, it is like she is in a straight jacket. When she has just got the three point harness on, she can move about. She interacts with you as you are going along pushing her (2Pi1:4).

The educational teams were more accepting but still offered views of a similar nature as justification for time limitations. Elizabeth's teacher explains:

She had a lap belt, a chest strap, a waistcoat and jacket, she had knee blocks and then obviously straps were... and we think it was quite... she didn't like going in it because she couldn't really move and that was really why she changed her school chair, but we thought she was so uncomfortable and she had all this strapping and her tummy was always kind of strapped it and it was quite a snug fit (1Tei1:2).

A number of the accessories are critical components of the postural management equipment, which the therapists explain, provide improved postural alignment of the trunk and limbs. Some accessories are a necessity; safety straps, for example, as the risk of a fall from such items is high. In the schools and day centre, the implications of this was never underestimated and transfer to and from such items of equipment, more often than not, involved two staff members. One person often took responsibility for securing the straps, whilst another often controlled moving body parts. A number of the participants also described how difficult this could be, even though hoisting was widely used. Elizabeth's teacher continues:

She would have a paddy, we would find it really difficult to get her in because she would arch her back and like throw her head back and her arms and legs would kick out and lash out and she would



cry and she would have what you would call a 'paddy' in a toddler because she didn't want to go in her chair and it would be quite stressful putting her in because it would need 2 adults and sometimes 3 adults to keep her, to be able to keep her sitting whilst we fastened all the straps up but it was stressful on us as well, we didn't like seeing her, you know she was having this huge paddy getting her so upset, she didn't want to go in the chair and we were basically making her go in it. So it was quite stressful to us and we didn't like that (1Ti:3).

Foot straps were often left unfastened, because if the child or young person had any control over their lower limbs fastening the feet was considered restrictive.

Yes, but they would never be fixed for long periods. It is difficult, she can get her feet out, she would wriggle and wriggle and wriggle and at the moment she has a different strap, but she can still get her feet out, she can get her foot out of her shoes, yes she can get her feet out. She does like her feet free, but we only do that if she is being moved around school to stop her kicking out (2Tai1:7).

However, priority for safety always took precedence and on occasion feet would be strapped onto the footplates of a wheelchair in specific situations in case the child kicked out and accidentally hit another child. The teaching assistant working with Hannah said:

Yes, but even if she does appear unhappy we would try to work out what it was. Is it her feet..., she doesn't like her feet strapped and we are having problems keeping the straps fastened at present. At times she does need her feet strapped, she caught me right on the cheek with her boot and it did hurt and that was because her feet hadn't been strapped in, and she pulls to get her feet out. She was in the paedro boots and they really are quite chunky (2Tai1:7).

Whilst a number of the respondents indicated that they would not like their feet fixed, decision making did not come easy. Stephen's mother explains:

He use to get quite upset at school when they use to fix his feet down and I asked them not to do that, but having said all that the footplate he can get his feet down the back because he likes to sit with his feet vertically down and because he is getting so tall now his feet drag along the pavement, so we might have to get some straps put on (8Pi1:4).

### ***Stretch and prolonged stretch***

The standing frame was one of the equipment items that often necessitated additional support from orthotics to enable feasible access, as existing limb contractures were present in a number of the children and young people. Leg gaiters were common adjuncts in use, requiring an initial manual stretch of the

tissues in preparation. The equipment then provides a more sustained period of passive stretch once the child or young person is positioned in the standing device. Detail appeared in the findings, the significant others were very aware of the responses by the children and young people, they spoke about negative behavioural expressions. Observations endorsed the responsiveness of the children and young people to stretch. The negative behavioural expressions were real, but sometimes short lived, albeit in some case temporarily. In most cases, it was reported or observed that tolerance restricted use; this due to the reappearance of negative behavioural expression.

I couldn't say he was madly keen because obviously he had to have the gaiters on to keep his legs straight. Well as straight as you could because his legs never go flat from the ground at all, there's always a slight bend (11Pi1:5).

He always complains. We're not, or we presume we are not hurting him, because once the task is done, he forgets about it. So we presume it doesn't actually hurt, he just doesn't like the initial stretch, but once we've got him there he usually accommodates to it (3Ti1:7).

The video transcript for Aiden and Peter, both disclose negative facial expressions, suggestive of distress during the manual stretch preparatory procedure, and resurgence when equipment tolerance reached, particularly for the standing device. However, in both circumstances, the staff appeared to anticipate the response, with positive engagement and interactions occurring throughout the application and the negative behavioural expressions short lived. The participants indicated that the child or young person settled into the standing equipment. This makes interpretation a challenge; distraction temporarily appeared to overcome stretch discomfort.

### ***Duration and fatigue***

Prolonged use of equipment, without respite was rarely a cause for concern in any of the children and young people in this study. The findings indicate that embedded routines and practices, or child characteristics in the majority of the thirteen cases had reduced the risk of these susceptible children and young people developing pressure sores because of sustained positioning. This is not to say the risk does not exist, and for two young persons in this study a history of former pressure sores reveals ongoing vigilance. All attentive caregivers whether it be those in education or health understood this risk, and only on one occasion was the pressure sore attributed to the adoption of a prolonged position

The parents, teachers, teaching assistants, key workers and therapists were all aware of this risk. Listening to the participants talk revealed how real attempts were made to embed a positional change into the learning day. Varying the postural position did not always involve postural management equipment. The participants spoke about hydrotherapy, time-out in the sensory learning rooms, the use of a beanbag or the floor. These less restrictive options portrayed positively by all the participants. Time out and the accompanying positional change potentially reduce high peak pressures over bony prominences, which may give some relief from positional discomfort.

The significant others spoke about time and equipment use. Table 9.3 gives participant estimates for those children and young people using standing equipment with limbs maintained in position with positioning straps and or orthotics.

Table 9.3 Duration of standing frame use by study participants

Cases	Standing frame or tilt table
Elizabeth	Up to about half an hour, 35 minutes, sometimes $\frac{3}{4}$ of an hour based on length of assembly.
Hannah	Twice a week for 30 minutes, except if not very good in herself or bored
Peter	Half an hour, maximum. Therapist aims for an hour.
Susan	No longer stands
Nicola	No longer stands
Janet	30-40 minutes maximum, twice a week
Aiden	Can tolerate standing frame for half an hour, but on another day might only be 5 minutes
Stephen	N/A
Ellie	30 minutes
Dominic	30 minutes if on a good day. He sometimes does not tolerate due to pressure on his gastrostomy peg, or general ill health
Phillip	Between 30 minutes-1 hours but after 10 minutes his face changes.
Vikki	30 minutes
Brendan	Initially 5 minutes, good day an hour, 3 times per week. As long as he is engaged in the activity

For some children and young people distraction throughout this period of passive stretch appears important. Tolerance was more of an issue with some children and young people than others were and some items of equipment tolerated for longer periods. The data also reveals the impact of other environmental conditions on tolerance levels, both positively and negatively. There was no doubt however that

the parents believed their son or daughter to be tired at the end of the school day, a report made by all the families.

### ***Positioning error***

As adaptive equipment is a personalized item, if the equipment is not used as intended the consequence may be a positioning error. In this section, I reserve exploration of errors to those causing the child or young person distress. Nicola's mother, classroom teaching assistant and therapist speak of their experiences, (Table 9.4).

Table: 9.4 Errors of Positioning Experienced by Nicola

Parent	Nicola's Classroom Support Assistant	Therapist
The position or she's uncomfortable and I know a few times she's come back from school and she hasn't been, she might have been a tiny bit out and she's crying all the way home and I know it's because she hasn't ... but I can feel the hip bone sticking on the side of the chair. She shuffles around and you can see her trying to get the hip comfortable cause of her hip, obviously I am not saying it causes her a lot of trouble but she has to get it into this comfortable position	I mean she has come in first thing in the morning and forever what reason she's got really upset and we just have to get her out of her chair straight away. I think it's because, I hope it's because she knows she can trust us knowing how she's feeling if something wasn't right, it could be her hip in her chair. It could be her AFO on her leg or something like that, anything. We just try to get her out the chair as quickly as possible.	Yes. One of the things that do cause her a problem is if her brace isn't put on properly gets red under her arms and she'll let us know that she's uncomfortable that way and we have to go and have a look and see why it's not on properly.

Aiden's therapist describes how positioning error might cause discomfort during transportation:

I think he is picked up at 10 to eight, and this will be five past nine and often people go take him off first because he is upset. That could be because he hasn't been positioned properly in the chair and he has travelled in an uncomfortable position, bounced around in the back of mini bus, sometimes it is cold, so it can be a combination, the crying. Once you take him out, give him a little cuddle he usually settles (7Ti1:4).

Often the position of choice is selected by the significant others, but if this is not acceptable it does appear the child or young person will react and others will respond. Dominic's mother talks about the postural position:

Yeah, they got to a stage with the chair that he wasn't going in it at all because he just wasn't comfortable straightaway. He was straight upright constantly and he gets a lot of trouble with his tummy in his peg so now he has a chair with a slight tilt, so it's

been great getting the right angle for him ... he's comfortable (10Pi1:11).

This was addressed at a later stage, but at the time it warranted parents to take appropriate action to avoid causing him further distress. Sometimes the reason for the positioning error is explicit. Dominic's mother explains:

Because the other night I hadn't actually realised I hadn't put the top strap on. I was in the street and I heard him crying and when I came back he was doubled over, he'd fallen forward and I just picked him back up and said sorry and he just smiled at me (10Pi1:9).

Other accessories contribute to the postural position, such as ankle foot orthoses and spinal jackets. Errors of positioning causing discomfort was not unusual

If he went to respite he would have them on and one day he came into school and they were on the wrong feet and caused blisters. After that they do not go to respite. We don't take that risk so, you know, when he is there he has a break from them as well. If he's still going to the centre we tell them to take off before he leaves the centre and then they put them on the next day (11Pi1:44).

If I was putting him in his wedge or if I was putting him in his standing frame and as soon as I put him he was objecting, I would change his position before I took him out, I wouldn't just take him out straightaway and say well that hasn't worked today. I would always straighten his legs a little bit or make sure his hips aren't twisted. So I would always try and change his position and see if I could leave him there just a few minutes to say, you know, perhaps he'll settle down, perhaps he just didn't want to go in the wedge today, but most of the time it's because he's uncomfortable and he's sore (7Tei1:11).

There have been quite a few times where the waist strap had cut into his back but I wasn't very happy about it at all (7Pi1:11).

The parents of Vikki, Nicola and Phillip were very receptive to the head and trunk falling into a less than satisfactory position perceiving this to be uncomfortable and limbs' becoming trapped an issue was raised by the parent of Ellie and Susan. The data reveals this variability, but also accounts for some of the variability. Phillips mother reports, you just have to say 'sit up straight'.

### **Avoidance**

One way of avoiding equipment discomfort is to not use the equipment in the manner intended, restrict its use, or make a conscious decision not to use certain items of equipment. The parents have an insightful awareness of their son or daughters likes and dislikes, and if they sense a particular accessory to be

restrictive and a source of distress, they modify use at home, a direction that does not appear to favour abandonment in totality. Elizabeth's parents insist she doesn't like being tied in the chair; they remove everything except the lap belt and allow her to move within the chair. Her behaviour they suggest changes following removal of this restriction. Hannah has a standing frame at home, but the family have only used it a couple of times. Father explains:

I suppose we should try a little bit more, but I suppose she has been in it quite a lot at school. It is like the splint for her leg we use to put it on before she went to school, but then when she came home there were imprints on her legs; it is not that it is too tight. But you know yourself when you take your shoes off at the end of the day, it is a nice feeling. I am not being obstinate in any way, but I do not put the splint on during the day. I have said to school is there any chance they can take it off before she comes home (2Pi1:2).

Janet is now in post-sixteen education, her mother speaking from experience has strong views and is explicit about the decisions she has made

As much as you would want her to have equipment and physio, it's nice to have that little break away from all that chore. It is hard work. Physiotherapy is hard work. It is hard work it is not easy is it. I saw her have it from 11 months. She started having it at home, she hated it with a passion, screamed the place down when they came, it use to work you up to death she continued to have it. It has done her the world of good but it is still nice to have that little break away (6Pi1:6).

Philip's family hold similar views about the benefits of therapeutic intervention and recognise the progress he has made over the years, no longer requiring the extensive head support and matrix seating system he had as a child. His current modular system supports him well. Phillip was one of the exceptions in this study as he remains in his adapted equipment on arrival home unless he is exceptionally tired; his family feel he is comfortable in this equipment as he does not complain and this alongside an ability, although somewhat limited, to self propel may account for this. On occasion when he is tired he also spends time on the sofa. Yet, the family do not take risks. He developed blisters, whilst in respite, because his splints were placed on the wrong feet. The splints no longer go to respite, but taken off before he goes, and then put back on when he returns.

Knowledge that equipment is rarely abandoned in its entirety in the home, except for the large space occupying items such as standing frames and tilt tables, possibly suggests an element of compromise enabling parents to fulfil their 'parenting role' without causing their son, daughter or even themselves distress. Phillip's mother

has not put him on the tilt table for a number of years; she knows he objects to the stretches. He always has but believes aims can be fulfilled, if he can be entertained during this process

So I've never believed in ... just because he was objecting to something or not doing that, which I think some people generally did ... I wouldn't do that. I would ...you know if the physio wanted something for an hour and I felt half an hour would do him good then half an hour it would be. Plus, you know, things did change slightly when he became 18 and you know they put more emphasis on his choice, well obviously Philip can't make proper informed choices and he doesn't know if he doesn't go in the tilt table he's going to end up like this, like that, whatever he's going to be like. So they have now accepted and it is documented in here that "parents said" he is to go on the wedge once a week for up to ..... well up to, well obviously the physio dictated the time but where, you see, they would ask him well do you want to go over the ..... well he would say "no", well that's not acceptable, it has to be done for his benefit and because I've seen such a change over the years, I know the benefit of, you know, equipment and exercises (12Pi1:30).

### ***Movement***

In this study, whilst all the children and young people experienced diminished voluntary adaptive postural control some moved too much and others too little. Those children who moved too much did find some respite in the use of adaptive equipment. One of the first items of equipment Ellie used was a corner seat. Her mother said she absolutely loved it; she could sit and watch the television without lying on the floor watching it. She describes transition to more restrictive seating

Even when she seen you pull it out she would go hysterical. Eventually we got her a bit more used to it when she realised she could do things, not herself but more freely when she was in it because she was sitting upright and she could play on the table top of it but she hated being in it, absolutely hated it. It took ages. Her new chair that she's got, we've only had since April, so I would have said it would probably took her a good year before she thought well I cannot get out of it basically. She did accept it to a degree, she didn't like being in it but she knew she had to go in it (9Pi1:4).

Movement, even atypical movement patterns, were clearly important to the child or young person. Ellie's mother said she loved the freedom of the floor and the idea she could move around from one place to another. The school staff also indicating she was happiest having unrestricted movement on the floor.

Peter, Janet and Phillip had gained some independence of movement using a wheelchair; and certainly within school and the day centre demonstrating its

preference over the alternatives of postural repositioning. On the floor, Hannah's movement control currently allows her to experiment with postural positions and postural changes. It gives her freedom to move around. The family understand why straps are in use at school but prefer her movements to be unrestricted. For the other children and young people with altered, restricted and variable movement patterns even small range may have some importance in the avoidance of discomfort.

Yeah, you can do because sometime you know when to un-strap her feet because she feels sometimes with her foot. It must be awful you know, having your feet strapped in, how many times do you cross your legs and wriggle your feet, have you feet in one position(4Tai1:11).

Whilst attempts were not always successful, the findings do reveal that Peter, Janet and Phillip could initiate some postural readjustments within a seated position. Uncertainty prevails as to whether this was in response to a discomforting sensation. All three also demonstrated some ability to move their trunk within their seated base of support. This was usually in response to an environmental stimulus, for example a social interaction or activity taking place behind them or reaching to make contact with a person or desirable object.

Peter who has some mobility on the floor feels secure in his wheelchair at school. He shows postural position preference, at home he sits on the sofa. His mum insisting that given the chance he would sit there all day and night. He sleeps in a similar upright sitting position. Sitting for such long periods I asked if he shuffled on the sofa, 'He does a bit, but I don't know whether it's because he is uncomfortable and moves to get himself a little bit more comfortable', his mother replied (3Pi1:8). During the interview, I saw Peter shuffle himself on the sofa. I said to his Mother at this point 'I see he has moved his leg and shuffled. So is that what he does when you say he shuffles'. His mother replied 'yes'.

Parents spoke of the equipment that restricted their son or daughter's movements, but also of the freedom, which gave release. For example Ellie's mother:

Fixed, she hates being fixed. Ellie loves to be free, she loves to be able to go where she wants to go and play with or do what she wants to do. She is a very determined child and she would be, if she could be, she would be the most independent child I think I have ever met in my life, but she just hated the straps and being put into that position and stuck in it. I mean even now, on the equipment we have now she's still the same and the equipment



now is more padded and it's more comfortable, she still doesn't want to be in them (9Pi1:6).

Movement was clearly important for Stephen the secondary school pupil who had bipedal mobility. With insight, his father describes his need for mobility:

I think it is more the case that he is active, rather than uncomfortable. Yes and it is exceptionally difficult to differentiate between, I am uncomfortable or I don't want to be here just that I need to be constantly on the go because of constant neurological activity because he has constant abnormal activity. He sees things in little blinks, obviously his life is like that, his movement is like that but there are times when he will sit at the bay window looking out, quite comfortably for some time. He does not like being in a stationary position and he will let you know by agitated movement, yet the minute he starts moving it he would be fine, So movement you might associate with the fact that he is going somewhere or the fact there are different things to look at (8Pi1:6).

### ***Postural repositioning and postural management***

A change of position at school or the day centre was common, and more often than not, the child or young person removed from their adapted wheelchair on arrival home. Postural repositioning as the time charts indicate invariably allow the child or young person to have an alternative position to sitting at some point during the day (Figure 9.2). The scheduled time for repositioning was easier to achieve for the younger children, but with careful planning and staff availability, it was an established aim for all and routinely reviewed at the start of each academic year. There were other less explicit opportunities for postural repositioning; for example, removal from their adaptive seating for personal hygiene. A seated position is not the position of choice for many curriculum activities which take place in a special school, in consequence careful curriculum planning indirectly dictates that the child or young person's position be changed if the curriculum is to be truly inclusive. This type of postural positioning does not always involve postural management equipment. In addition to adaptive seating the standing device was the most used item. Other items were in use, for example wedge and corner seats, but postural repositioning appeared to take precedent over postural management. Free lying on floor mats, beanbags and mattresses in the soft play sensory room all offering respite from the seated position.

The therapists however perceive the need to give attention to postural management as a means of managing comfort. Peter's therapist states 'if he is not quite central I know he is going to start complaining so we have to get him right to be comfortable, so I suppose it is practice'(3Ti1:6).

Well you try to get her midline her hips in midline as well as well the best you can, although I know that Susan's got one leg longer than the other, problem with the hip. So you try your best.... lined up really, the best you can, make sure there is nothing..... she's got a permanent sling under her so you must be aware that it must be as smooth as possible because, you know, if she marks quite easily and to try and change her position as much as you can, as often as you can, bean bags, back in her chair, back on the bean bags, lift her out of her chair, just alter her positions as much as you can (4Tai1:5).

Yes if he is in his seat properly, he will tolerate it, if he has not been put in properly and his bottom is not right back and his pelvis is forward then he will not tolerate it past about 20 minutes and he will start to shout and he will moan and groan until somebody comes to sort him out (3Ti1:3).

### ***Aesthetics***

Without a child or young person, the item of equipment becomes a detached object. In this study, the significant others judged appearance using words to describe shape, form and texture. Appearance, for many participants remained important in terms of judging its comfort. Aesthetically pleasing items were judged more comfortable than others less pleasing on the eye. Words such as, comfortable, relaxing or 'comfy' were used to describe equipment that was pleasing on the eye. Standing equipment was not subject to the same scrutiny; perhaps participants sensed that unlike adapted seating use would be more restricted. The participants spoke of the equipment in isolation, and at other times vision processing was used to perceive its functionality and the physicality of a comfort, discomfort dimension for the child or young person within the equipment. For the educational staff in the classroom and parents, equipment was compared, and aesthetics frequently used for this comparison. The rigidity of a wood seat, either current or in the past, was of concern to a number of parents who perceived such equipment to look uncomfortable. Ellie's mother:

Initially I just didn't like the look of it. I didn't want my child in something that was different to what any other child had, which is most parents, you don't want them to stand out and be different. It looks like a torture chair. It was horrible to look at. She hated being in that ...(9Pi1:4).

So it's like she's really like one of these disabled people that is going to really harm themselves and part of her symptoms is self harm. She's really strapped so she can't move. I looked at it one day and I expected her head being strapped to the back of the back rest and I looked at her and I was horrified (2Pi1:15)

That is the only modern one they do, I wanted something that was modern, and I didn't want something that was really ugly. I am still young (7Pi1:8 ).

In summary the findings reveal past history of physical factors which are portrayed by significant others as causative of discomfort, with the views and experiences also revealing customs to achieve comfort.

## **Consequences**

This final section culminates with consideration of the consequence of actions to manage the antecedents of discomfort. If a discomfort was present and addressed, the child or young person became more content. However, the findings also reveal times when the children and young people were content, and responsive to situational happenings with no evidence of a possible discomfort. This helped interpretation of a comfort state.

Sometimes the significant others cast doubt as to whether the equipment was always the cause of more negative behavioural expressions, they also described other factors, which were a source of distress. I asked Brendan's therapist how tolerant he was of his equipment

Very tolerant, he loves to be part of the group, so if the group are all in cookery he likes to be part, be in the mixing bowl, and if the position enables that he is very happy. If he is stood up out the way and everybody else is around the table he won't be happy (13Tei1:2).

The embodied child or young adult had other needs, the significant others spoke of need for human contact, attention from adults, or for some other basic human need to be met. In times of distress, whether or not the equipment was causative the children and young people were comforted. These times often saw removal of the child or young person from the equipment, this very act, irrespective of cause gives opportunity for a postural repositioning change which itself must bring about some relief.

## **Relief**

On a number of occasions I witnessed distress. Unless physical contextual clues were obvious my 'knowing the child or young person' was far removed from those who did. Yet, when the child or young person was comforted some relief was observed, and the negative behavioural expressions, not exclusively, but often

abated, particularly when the child or young person was removed from the equipment. Aiden's teacher described his response:

Yes and he responds really well to being picked up. We can't pick him up too often because he knows that if he cries someone will give him a cuddle and snuggle him in so he cries even more but he likes to be picked up, he likes to be moved and he responds quite well to that (7Tei1:8).

I asked Aiden's mother how he responds to removal from adaptive equipment: he laughs was her response. Dominic's mother said, 'he'd be happy sort of straightaway. Or if he's still not happy then we've got to take him out and give him a cuddle.' If not the problem solving continues. If the source was due to a physical discomfort, attention to the source brought change. For example, Nicola, on arrival in the classroom one morning was distressed; her thoracic support had moved putting excess pressure under her arms. Removal from the adaptive seating followed by readjustment appeared to resolve the situation and she was replaced in the seat with no further signs of distress, a state of relief if the source was equipment discomfort, and the potential for an 'at ease' state to be achieved.

She [Nicola] smiles and she just relaxes really, doesn't she. If she's up to the point of distressed. I think you can immediately see the change, once she is out of her situation, more comfortable and you can just see it all over her body (5Tei1:11).

### ***Ease and functionality***

In the communal areas of the school and day centre, few positioning alternatives existed; adaptive equipment did provide a position of safety and functionality, and wheeled seating a means of regularly experiencing life outside of the special school or day centre. A further look at purpose proposes interplay between the child and young person: internal bodily events imposed by equipment use and external environmental demand conditions. Distress free use of equipment was often purposeful use, revealed in rationales found in the narratives. I asked Aiden's teacher about positioning preference

In his school chair because he is upright, he is fastened in so he's nice and safe but he's fastened in so that he's in an upright position and he's got a tray and his hands rest on the tray and it kind of pushes his head up. When he hasn't got his tray on, because sometimes he doesn't need his tray, his arms are then on his knees and his head goes down so you can't get as much interaction, but when he's in his school chair, he's got his tray on, he's more upright, we get a lot more out of him (7Tei:15).

Consistent responsiveness as an indication of positive and negative affective feeling, alongside contextual and conditional detail, can provide observers with sufficient information to make judgements. The participants spoke of contentment, and described the behaviours of the child and young person.

The findings abound with example of distress free, purposeful use of equipment, which appeared to give the significant others, including myself, increasing confidence that a state of ease and acceptance of equipment use was achievable. Some notable examples including access to the outdoor play areas, circle time registration, school assemblies; negative, prolonged expressions were infrequent.

In the school situation, more often than not, an activity, a lesson, a personal care activity, a play or free time activity is pursued; the equipment and its origin of implementation having an identified functional purpose. There were many occasions during the course of this study where the participants spoke of children and young people functioning well in the equipment, more so with the adapted seating. The teaching assistant describes Susan:

...a science lesson she would access. last week we did things that dissolve, so Susan felt them before, there was ice and sugar, there was flour. She wouldn't be on the beanbag then, she would be in her chair with her tray on so she could feel, so when they dissolve she can stick her finger in, stick her hand in. I mean you would get her hand and put it in it, watch her reactions, if she takes it away maybe she doesn't like it, she explores (4Tai1:8).

For educational development, Brendan's teacher preferred him to be in his adapted seat:

I think it is because he is at your level, he can get good eye contact, he's got his tray which he can work and play on which you can put his gaiters on, he has gaiters for his arms, he can do more things, like with switching (13Tei1:5).

If situational opportunities were appealing to the child or young person there could be expressions of happiness. At other times they simply appeared at ease, in their surroundings or with the activity in which they were currently engaging, with no observed discomforts or negative behavioural expressions. The significant others spoke of contentment in describing the behaviours of the children and young people but some meaning was also found in the successful, protracted and repetitive of use of some items, particularly the wheeled adapted seating systems. Phillip's mother said:

The seating ..... apart the corner seat, you know, the moulded seat or whatever, he has no choice, that was it, I'm afraid. Obviously he didn't get distressed or he wouldn't have been in it, I couldn't have done that. The corner seat used to be, I think we used to do about 20 minutes (11Pi1:5).

The teaching assistant in Peter's class said he loved his chair, she said it was his comfort zone. Janet's teacher said Janet's complaints are with standing and that she becomes uncooperative if she does not want to stand, which is more noticeable after the holidays when she hasn't stood for some time. Yet her wheelchair is different, teacher said she never complains and does not feel she is uncomfortable. She reports:

I think there are times where if she's been having a lot of seizures and she looks tired I would give her the opportunity of coming out and going on a beanbag but often she will turn you down. I think she likes to be in her wheelchair because that's her mobility; to take that away so she is probably more motivated to stay in regardless of how she's feeling because she's got that mobility.

I similarly observed and video recorded children in the classroom and young people in the day centre and perceived the equipment to be successful enabling access to the pre-planned curriculum or programme. The children and young people appearing neither happy nor unhappy, just at ease and engaged with the task or activity in hand. This status would founder if comfort measures and authentic caring practices were unattainable. This successful and effective use of equipment as portrayed by the participants aids understanding of comfort.

Yes, you always have a problem getting the gaiters and getting him onto the wedge is the hardest, you know, I mean it takes at least 2 of you to do it because of it being on the floor. But no, he's fine when he's in that because he usually has something to play with in front of him.

An inanimate item of postural management equipment itself is not pleasurable, as observed in a number of the children and young people, purpose and task contributed to a state of engaged contentment or even as suggested by Aiden's teacher, a state of alertness with no unhappiness signals. Justification for use could be a seating system for classroom engagement in curriculum activities, or a supportive armchair for relaxation. Use of equipment in school assembly was an excellent example of the children and young people orienting well with their environment.

## ***Distraction***

Distraction in the form of someone or something that diverts attention away from equipment induced discomfort was observed in the school and day centre, and parents spoke about this at home. Ellie's mother:

I mean you could put her in and sit her in front of the telly and she would watch the telly but that wouldn't last long. Her concentration is not great so the need to entertain while she was in the chair was there. You couldn't just sort of stick her there and think oh well she's sat in the seat, she would be quite happy, that just didn't work (9Pi1:7).

Ellie's mother said that 'if she was in a good mood and you could entertain her without her sort of getting bored she could be in there an hour, even longer sometimes, other times she can be in 5 minutes'. One day during observations, I watched Peter using the tilt table, which likely induced a passive stretch to his lower limbs. He was with class peers, positioned in a semicircle facing the interactive white board. At times, his face looked strained, but once the teacher's attention focussed on him his demeanour changed. The team liked Peter to stand in assembly, which was usually was 30-45 minutes in length and in primary school took place at the beginning of the school day. The teaching support assistant said 'I mean if he's singing and what not, so his mind is elsewhere then, he does tolerate it better I think when he's in assembly (3Tai1:6). Likewise standing, using the tilt table became part of Phillips's care plan following transition from school to adult services. A few displeasing grimaces occurred during splint application, but likewise he thrived on the attention and cajoling with staff brought about during the hoisting transfer. Staff and parents sensed Phillips's displeasure brought about with standing. His father said 'I would imagine it's good that they incorporate it when they're having their team meetings so at least the team meetings is maybe taking his mind off him being in it'(11Pi1:24). Observation of Philip's video saw changes in expression when left alone on the upright tilt table, even in the presence of motivational activities; his trunk posture suffered a slump to the left. Reinforcing engagement with an adult during the above activity brought displays of happiness back to his face, and a willingness to continue with the activity. Phillip's mother:

It's trying to amuse him and take his mind off. That's what we've tried to do over the years when, you know, obviously we have had equipment at home when he was smaller and we've put him over the wedge and he's never been mad keen 11(Pi1:25).

Brendan's therapist says he gets bored very quickly if he is not stimulated, gets fed up and then starts to whinge and cry and will then try and make something happen. Equipment tolerance she believes is manageable.

He loves to be part of the group, so if the group are all in cookery he likes to be part, be in the mixing bowl, he likes to be part of the group and if the position enables that he is very happy. If he is stood up out the way and everybody else is around the table he won't be happy, and this year he is in with the crowd and he likes to be part of his peer group (13Ti1:2.).

But unlike Peter the distraction of assembly did not work as well for Brendan. The following conversation between myself, and Brendan's teacher explains her views

Te 13: I think he is uncomfortable in standing frame  
Int: is there anything that leads you to believe that that he is uncomfortable?  
Te13: just his vocalization, he vocalizes a lot when he is in his standing frame and it's not, it's an unhappy vocalization  
Int 13:Unhappy  
Te 13: you can definitely tell it is an unhappy vocalization, so I think, unless he is just having us, which Brendan can do  
Int 13: You mentioned that the standing frame tends to be used more in assembly, does he still have that unhappy vocalization?  
Te 13: yes, which is something he enjoys. If he is in his chair, he enjoys it and if I haven't put him in his standing frame he is very happy, he likes the singing, he likes the songs, the music, so that's what makes us think he is, because he is unhappy, that he is uncomfortable, sorry. However, if he is one to one is his standing frame with sometime (name) the physio assistant, then he will tolerate it so I think he is uncomfortable and he is just tolerating it because he has company with him, yeh, on a one to one basis.

As the analysis of data for the first case, Elizabeth, progressed it was rewarding to see the fruition of data triangulation. Both the teacher and therapy assistant spoke of Elizabeth's enjoyment of standing in school assembly. In the primary school, I soon discovered that assembly was the time most of the children stood in this type of equipment, whether it was the standing frame or tilt table. Space was at a premium in the large hall, a comment made by the teaching staff. However, more important was the setting. The assembly itself, with the creation of music, laughter, noise and the sound of happy children. As other children became my 'cases', I sat on the perimeter of the assembly during my visits and realised that Peter, Aiden, Ellie, Dominic and Brendan also responded positively in this environment. With certain distractions, the children appear to cope with potential discomforts. Only on



one occasion was a child removed from assembly. This was Brendan, and later that morning he was vomiting.

## **Summary of findings**

The thirteen children and young people in this study used adaptive equipment, decided upon by significant others in varying contexts. Six children attended a primary special school, three a secondary special school, a further two in transition to full time educational and two attended an adult services day centre. In the school/day centre setting, therapy identified goals for postural positioning programmes were in place, alongside curriculum content and care plans. However, it was the established daily routines for the parents at home and the staff in the classroom or day centre, which underpinned both actual and purposive use of equipment, accordingly having an indirect impact on both comfort and discomfort.

All the communicative signals of the children and young people given relevant meaning were situational interpretations within the identified contexts. The facial, vocal and movement expressions in some appeared more affective, intentional and discriminatory than other children and young people. Such signals may have several meanings, but over time the significant others gradually build up practical knowledge in recognising and interpreting the more subtle idiosyncratic clues. The more obvious emotional clues of negativity were less frequent in those reported as having high pain thresholds. Yet the occurrence of a grimace in response to an action, known to cause discomfort to others in similar circumstances, and to others in this study I observed or it was reported. Although the behaviours observed appear to be related to situational and physical clues, these responses may be more akin to attention or orienting response than to intentional communicative acts in some of the children and young people. However, in all settings, the children and young people were able to affect attention of significant others and had their needs addressed. The behaviours attributed to a discomfort experience could be attributable to other sources of distress and validation difficulties must therefore be acknowledged.

Equipment usage was about having practical purpose, but ongoing use was associated with at least a visual appearance of contentment. With no emotive display of unhappiness, equipment use was consistent with the duration of use maximised. A behavioural expression of happiness was therefore not a prerequisite, but often an alert responsiveness or an emotive display of happiness more often

followed adult or task engagement. The child or young person who displayed unhappiness signals initiated empathetic, concerned responses in others.

Parental obligations and routines varied across the cases. For them the daily challenges were often arduous and time consuming. Yet, need for equipment was not denied and its use at school rarely challenged; however, what the parents did acknowledge was their son or daughter's entitlement to a freedom from school or day centre exertions whilst at home. They made decisions with regard to equipment use, amid findings to suggest that past discomfort events and associated behavioural expression were factors influential in the setting of daily routines. Although, in some occurrences this appeared at odds with professional decision-making, the decisions taken were nonetheless transparent.

In the school and day centre, collaborative working enabled postural management to be embedded into daily routines, albeit not always sustainable. A planned, structured school curriculum, and documented care packages for those attending day services, did however appear to offer the most scope for postural re-positioning, if not postural management. This is because some events, which involve re-positioning, necessitate an obligatory care act, an example being personal hygiene. Alternatively, the event requiring a posturally changed position is an established and enjoyable core curriculum activity, such as hydrotherapy. Both with the potential to offer some relief, particularly if they follow a period of more prolonged positioning restriction. The findings also reveal unplanned events that often challenge practitioners in the classroom; events, which may or may not affect planned strategies of action for those using adaptive seating or postural management equipment.

In summary, a 'comfy' appearance of the inanimate equipment was reassuring to the significant others. Moreover, if the child or young person also appeared content the equipment was perceived to be functional. The factors believed to be causative of discomfort included positioning errors, preparatory and prolonged stretching, and movement restriction but prolonged unrelieved pressure over high-risk body parts, sufficient to compromise tissue viability, was in this context currently not a concern factor. Caregiver experiential awareness of risk produced vigilance.

The majority of the children and young people could not alone bring about their own relief, and the presence of a discomfort more often than not prompted the significant others to take action to eliminate its source. However, preparatory stretching and prolonged stretching found to cause discomfort was not abandoned as this was felt

to be therapeutic, even in the presence of negative behavioural expressions. Some distraction may be possible.

Equipment, as individualised by others, provides the child or young person with a microenvironment from which to function, but the global environment manipulated by others appears equally important with regard to outcome, and perhaps more so with this group of children. These children could not benefit from group inclusion in the classroom without strategic planning, and in the current study this was provided by attentive individuals / teams who mapped achievable attainments.

## **CHAPTER 10**

### **CONTEXTUAL UNDERSTANDING OF COMFORT AND DISCOMFORT: A DISCUSSION**

#### **Overview of the chapter**

The purpose of this study was to extend understanding of how children with profound and severe physical, learning and communication difficulties experience and have their comfort needs met when using adaptive positioning equipment. As the children and young people could not express their own comfort or discomfort using language, in reality much uncertainty will remain. In pulling together the main findings from the previous two chapters and integrating these with key empirical and theoretical works my aim in this chapter is to make sense of the findings.

In chapter 7, I explained how the following four perspectives achieved relational connectedness between the cases capturing the essential qualities of this contextual exploration. I will discuss each in this chapter.

- Experiences owned by the child or young person
- The contribution of others to the experience
- Situational clues
- Comfort and discomfort: connected and independent

My first research question that asked how a child or young person communicates an experience allied to comfort/discomfort brought the children and young people to the fore of this exploration. In the thematic analysis, issues of meaning emerged from each case and I interpreted the non-verbal behaviours of the children and young people, as described by myself and others, as adaptive responses to either an internal bodily stimuli, the microenvironment of equipment use or an environmental event. Emerging both from the literature and from the participants in my study was the topic of communicative signals, the possible means of expressing comfort and discomfort experiences; this expressivity affected others. Whilst coming to this study with some personal knowledge, my second research question recognised that I needed to seek out further assistance from people who had a special relationship with the children and young people. Although the parent, teacher, therapist or teacher support assistant cannot experience the inner comfort or discomfort state imposed by postural management equipment, the second theme extends discussion to these knowledgeable communicative partners, their attentiveness and any organisational routines which influenced any of their judgements about equipment.

'Home is home' was a strong sub-theme, which re-established the child or young person as a family member, entitled to respite and relaxation at the end of the day. The third theme involved unravelling the tangled layers of multifaceted findings to consider the antecedents of comfort and discomfort. The underpinning action strategies to achieve comfort varied, but in the presence of a possible discomfort, the approach for all was one of immediate trepidation with reciprocated decisions and actions often necessary. Whilst often placed on a continuum, discomfort and comfort become individual entities in the final perspective. The findings that relate to the children and young people being at ease in the equipment and using it functionally are reviewed and developed, taking into account existing knowledge.

### **Experiences owned by the child or young person**

As the children and young people demonstrated change in their level of responsiveness and communicated using behavioural expressions that were interpreted by a communicative partner I have elected to subdivide this first section of the discussion into these three areas.

#### ***Internal bodily states and environmental responses***

In aiming to give 'voice to the child or young person', but still grappling with subjective ownership, I found the words of an early writer in the field of learning disability particularly useful. Kephart (1968) describes the adaptive response as occurring through the mediation of sensory motor experience, with the person 'coming to some kind of acceptable terms with the environment' (Ayres 1978, p.36). Whether these responses were socially learned or biologically determined signs and signals was out-with the remit of this study, but for each child or young person these were interpreted in the context of this study as the reality of an experience of a situation or response to a bodily event.

Dissimulation of non-verbal expression is taken seriously in persons without intellectual difficulties who experience pain (Hill and Craig, 2002), but it is doubtful the children and young people in this study had the capacity to fake their responses. The classic findings of developmental and behavioural researchers who studied behavioural state and non-verbal affective behaviours as expressions of emotion in infants and children (Izard, 1982; Wolff, 1963 and Wolff, 1969 in Wolff, 1987) and more recent investigations into behaviour states and expressions of persons with profound multiple disabilities give status to the current findings. In particular, for those children and young people who at first glance appear to lack environmental engagement, Wolff's monograph (Wolff, 1987, p.14) describes the continuum of

behavioural and physiological conditions in infants, both behavioural state as a causal analysis of behaviour and the presumed functional meaning of emotional expressions.

An interest in raising levels of alertness in learning environments led researchers to look more closely at behavioural states (Woodyatt *et al.*, 2004; Arthur, 2004; Guess *et al.*, 2002; Mudford *et al.*, 1999, 1997; Ault *et al.*, 1995; Guess *et al.*, 1995, 1993; Richards and Sternberg 1992; Guess *et al.*, 1988; Rainforth, 1982). Throughout the late eighties and nineties, Guess and colleagues first proposed and then investigated the influence of behavioural states on the levels of responsiveness in persons with severe developmental disabilities (Guess *et al.*, 1988; Guess *et al.*, 1990; Guess *et al.*, 2000). Individuals who were unable to communicate a level of interest in an activity appeared to show observable changes in alertness; thus enabling these research teams to conclude that behaviour states were 'real and consistent expressions of behaviour'. More recently, an expert panel in the field of intellectual and multiple disabilities (Munde *et al.*, 2009) concluded that two aspects must be part of an alertness description: a theoretical concept describing the internal processes that cause different alertness levels, and reactions to the environment, which becomes visible in the behavioural aspects of alertness. The findings from the current study are not contradictory to this conclusion; the significant others in this research spoke about their responsive action to pain, elimination discomforts, fatigue, pressure discomforts and mood of the child or young person. They linked these to expressive facial, vocal, and body movement behaviours. A responsive action by the caregivers to initiate a positional change occurred more frequently in response to a changed behavioural state, especially when the adaptive response was a cry. Adaptive equipment per se may not be the stimulus that prompts the behavioural change, except if it is painful or uncomfortable. However, reducing postural positioning due to lack of behavioural responsiveness on the assumption that the child or young person is comfortable would also seem to be unwarranted as this could relax caregiver vigilance.

The need to explore the interrelatedness of factors within educational programs that are relevant as opposed to the use of behaviour state information in discrete aspects is the focus of research in the 21st century (Arthur, 2004). This developing knowledge base undoubtedly gives crucial meaning to behavioural states interpreted by the significant others in the current study, which habitually lends support to the notion that particular antecedents, including equipment use, can

produce a number of behavioural expressions and communicative conditions. Excepting one young person, facial expressions and vocal sounds were detected as the most influential interactive signals, albeit interpretation of the stimuli or denomination of the internal state at times being difficult. In Elizabeth, Nicola, Ellie, and Vikki stereotypical facial twitching and or facial muscle spasms were common and the expressions more often irregular and quick. Nonetheless, some change of state was perceived as detectable, the cry or agitated state was not a state which the significant others in this study struggled over. All were aware of acute 'pain states' in the children and young people, often recognised because the expression was extreme and persistent. Other clues help identification of cause. This finding is important as it gives recognition to the presence of a bodily state before the pain as such existed, thus giving authenticity to transitional possibilities between bodily states. In the nonclinical context of everyday living if discomfort exists and is recognisable, a state without discomfort is therefore available for comparison. Adaptive equipment as an adjunct to the provision of a learning environment was not a variable extensively controlled for in the above mentioned studies; although, Richards and Sternberg (1992) found that the sitting position was not clearly associated with any particular state level. Whilst of different methodological design, the findings are not dissimilar to the current findings; children and young people can appear both at ease and then distressed in the same item of equipment.

### ***Behavioural expressions***

In the current study the significant others affirmed the categorical nature of the expressive behaviours, and some offered judgment about associations. It was the distinguishable, negative, emotional expressions, perceived to represent unhappiness, which prompted immediate and responsive action. Although positive expressions, of perceived emotions of happiness, were additionally and frequently described. This finding was important to my interpretations of comfort and discomfort as expressivity is behavioural change that usually accompanies emotion (Konz, 2008), which is perceived to be contributory to subjective wellbeing and quality of life (Colver, 2008; Schalock and Felce 2004; Hensel, 2001).

Negative life events, such as pain, can affect a child's quality of life (Arnaud *et al*, 2008; Dickenson *et al*, 2007) and a number of the significant others in this study confirm the negativity of events some of these children and young people have endured during their lifetime. The parents had no difficulty reporting what they believed to be the behaviours indicative of acute pain, an event they considered

both unpleasant for themselves and their son or daughter; those documented in chapter 9 have some similarities to findings reported in the contemporary literature. On other occasions, the reality of the child or young person's experience sometimes evaded disclosure, but the less preferred responses suggestive of displeasure, discomfort or distress in comparison to more pleasing behaviours were difficult to dismiss. Crying, moaning, body movements and a facial expression of negativity were common descriptors found which the general population also associate with distressful emotions or unhappiness.

In clinical practice and pain research facial expression has emerged as an important pain indicator. On going study of judgements of facial expression has offered a way to understand the perception of the suffering of others when an individual is unable to self-report pain, and several pain assessment tools are now available (LaChapelle, Hadjistavropoulos and Craig; Schiavenato *et al.*, 2008). There is agreement over the specific facial movements that accompany the emotional negativity following exposure (Kunz *et al.*, 2004; Le Resche and Dworkin 1984). In the current study, where the significant others felt they were able to identify discomfort as opposed to pain, the reports were of less extreme expressions, with all except two of the cases displaying expressions known to have nuances linked to negative emotions. Forthcoming also was recognition of happiness and contentment; again facial expression were prevalent. The significant others appeared sensitive to some grading of expressions.

Prkachin *et al.* (2004) found there was a linear relationship between the density of exposure to strong pain and the criteria used by observers to judge response; greater exposure was associated with more conservative decisions, with the participants in their study showing a very high level of sensitivity. This study also provided evidence of an adaptation-level effect in the judgement of pain expression meaning that in psychophysical judgment tasks, the evaluation that an observer makes of a stimulus may depend on the context in which judgments are made. This may account for marked difference between co-workers in multi-person environments. However, in the current study, expressions described were similar across the data sets, with the contextual and personal knowledge of significant others appearing to account for some of the consistency. Behavioural expression in response to pain occurrence did not preclude the appearance of similar negative emotion responses to other experiences, although with some grading. Le Resche and Dworkin (1984) prompt discussion asking the question 'are the behaviours expressions of pain or reactions to it', stating that the appearance of one emotive



expression may not preclude the appearance of other emotion expressions in close proximity, such as fear, anger and sadness.

As a way of enhancing aspects of daily life in persons with profound intellectual and multiple disabilities, investigators have studied behavioural expressions using a socially validated observation system to record indices of happiness and unhappiness (Petry and Maes, 2006; Green and Reid, 1999; Ivanic *et al.* 1997; Green and Reid, 1996; Favell *et al.* 1996). The findings from these studies show promise as they demonstrate that indices of happiness and unhappiness can change differentially across activities and environments. This suggests that displeasing events, other than pain can result in displays of negative emotion. Such findings lend support to the beliefs of the significant others in the current study that sounds and facial expressions did portray pleasure and displeasure and positive and negative moods. Albeit they acknowledged that distinguishing between less overt stimuli sometimes required the enlisting of other reasoning strategies.

The facial expressions were the behaviours described by most of the respondents, but other non-verbal behaviours made a contribution. For Susan, 'hand flapping' was an important contribution to the decision making in regard of expressions of unpleasantness or dissatisfaction. Another one of the young people in the study had a health condition with the clinical features known to have stereotypical facial movements, but the significant others were still very aware of facial emotions. In the first instance it did appear the significant others were interpreting their observations from facial expressions of happiness or distress, although additional cues aided interpretation. When I returned to the field study sites with the video recordings the significant others had no difficulty interpreting the happy or distressed facial expressions; however in those video images where only the face was viewed they struggled to comment on the type of state which might have lead to the facial expression. The availability of contextual information therefore appears to be important for interpretation of equipment comfort and discomfort.

### ***Communicative interactions***

The form of communication in a small number of the children and young people was symbolic. Peter, Janet and Phillip could direct attention; they used nonverbal intentional behaviours to indicate their feelings about a particular event or activity. This included the usage of equipment. All three had some control of their upper body; this was immediately demonstrable because of their ability to use their upper limbs. In the analysis, the illustrative accounting of communicative function for these

children and young people included demonstrative emotions, pointing, and some activity preference or rejection. Some described events could be attributable to the displeasures of using certain, but not all items of equipment. For Peter, Janet and Phillip standing was one such activity, accepted but less pleasurable than other activities.

In the previous two chapters I reported observation of facial grimaces during preparatory stretch techniques, interspaced with communication strategies, followed by the appearance of more positive affective emotive behaviours, and then the resurgence of those grimaces appearing as the process was repeated with the other limb. In the same way that the children and young people who participated in the preparatory phase of this study verbally communicated the presence of discomfort in the interviews and focus groups these three individuals provide some testimony to the positives and negatives of equipment use. For Peter, Janet and Phillip there was perseverance with the use of standing equipment, but in all cases this was short-lived. For Peter and Phillip the preparatory grimaces were evident, Janet's reluctance was extreme. Where the child or young person acknowledges the presence of, or communication by, a partner and demonstrates compliance with a routine or exchange or activity, Foreman *et al.* (2007) identifies this as an important communicative function. The interactive reassurances by significant others, in the case of Peter and Phillip, allowed for continuation of the therapeutic intervention. Even for the symbolic communicators interpretation was not always an easy process, and often this still warranted the communication partner to engage in a process of elimination. The ability of the child or young person to indicate some preference was however apparent with standing interpreted as less pleasurable.

At the outset, the intention of my focus was to be the non-verbal behaviours and availability of physical cues as causative factors; however, the discussion of behavioural states and expressive behaviour compelled me to give additional meaning to the nature of these behaviours. As reported in chapter 9, this was because of the greater challenge to give meaning to the interactions came from those children and young people who only communicated in pre-intentional and non-symbolic ways.

In infants before the emergence of communicative gestures, emotional expression is the only way for an infant to communicate his or her needs. The infant cry is a sign, but understanding of function occurs in a context that includes reception and interpretation of the signal (Barr, Hopkins and Green, 2000, p.2). According to

attachment theory (Bowlby, 1969; and Ainsworth *et al.*, 1978 in Spangler *et al.*, 2001), a negative emotional expression is an attachment behaviour activated when an infant is distressed or anxious, its function to activate the complementary care giving system of the parent to enlist support and comfort (Spangler, 2001). Emotional expression is thus a substantial component of infant caregiver interactions, but the presence of a communicative partner is important. The children and young people in the current study are no longer infants. However the non-verbal behaviours were more than just signs; for the responsive parents, professionals and direct support workers who had close relationships with the child or young person, meaning was given and the signals were interpreted alongside other clues. Often the emotional expressions were the only communicative signals of affect present for interpretation by the significant others. Therefore activation of this complementary care giving system as proposed by Spangler (2001) appears possible. In the current study, occurrences of non-verbal behaviour, even though non-conventional in comparison to a typically developing infant, appear therefore to function in a similar way and enlist social response in others. Attribution of communicative intent by the child or young person to either comfort or discomfort was in this context dependent on dyadic interactions. The mother of one of the pre-school children as described in chapter 9 initially had doubts.

Yeah. I mean somebody told us you would know when he's uncomfortable, you'll know when he's like not happy and things and I was like well how, he can't tell us, but we have learnt his different whines. There's a whine when he's like bored and there's a whine when he's generally upset and then he has like his proper crying (C10Pi1).

Granlund and Wilder (2006, p.177) state

to ensure that interaction takes place for a child with multiple disabilities, an interaction partner needs to have knowledge about the child's characteristics, skills, mood, preferences and behaviour style as well as context.

The current study did not set out to study interaction patterns between the communicative partners and therefore no theoretical perspective from those participant communicative partners was possible. Nonetheless, the parent, professionals and direct support staff did give meaning to the signals, the idiosyncratic behaviours and changing states, often in a differential manner. They recognised changing states, which they related to a number of internal processes: hunger, equipment discomfort, activity, attention seeking, pain, pleasures,

enjoyment, happiness, objects, interactive stimuli, unfavourable stimuli, bowel function, fatigue. Some they recognised as been influenced by external stimuli.

As communicative partners, the significant others did use words. This language element as discussed by Hostyn *et al.* (2010) instantly presupposes inequalities in the partnership; yet giving recognition to this asymmetry they believe is 'as an intrinsic property of dialogue which corresponds to the reality of engaging with persons communicating at a pre-symbolic level'. They, in keeping with Olsson (2004), favour a dialogical, rather than traditional information processing approach to communication and human interaction. Hostyn (2010) states that communication partners using the dialogical approach 'simultaneously engage in a process of meaning making they mutually influence each other and there is a continuous interaction and adaptation'. The following definition of communication: 'occurring when the behaviour of one person is assigned meaning or intent by another' offered by Grove *et al.* (1999) is a reminder that in the context of the current study the efficiency of a communication interaction depends on a mutual adaptation process. The identification of predictable behaviours, by communicative partners, can set the occasion for a response even if the initial observed behaviour does not serve a particular function, responding consistently to this action as if it might may over time serve to establish that response as an effective form of communication behaviour (Sigafoos, Arthur Kelly and Butterfield 2006; Sigafoos *et al.*, 2000).

In summary, for postural management and postural positioning the children and young people in this study are dependent on significant others, a process that should entail reciprocated responsibility if these care giving actions are to be person-centred. The significant others spoke of communicative intent; the communicative acts were interpreted as intentional and they had an effect. In this study, the significant others then took responsive action.

### **The contribution of others to the experience**

The parents, teachers, therapists and teaching support staff were all directly or indirectly accountable for transfer of the child or young person in and out of the equipment, and thereafter manner and duration of use. These professionals and caregivers, as the significant others, become the focus of discussion in this section. Not owning, but indirectly contributing to and influencing the sensory experiences for the child and young person they undoubtedly placed equipment comfort and discomfort in the background of the wider picture of daily routines that are

necessary at home and school or day centre. The parents, however, experience adaptive seating and other items of equipment in the context of family life, and the teachers, therapists and support workers in the context of their professional orientations within multi-person environments. Each was subject to the organisational and routine conventions of context, which influenced equipment use on a daily basis. Often the processes, which led the decision maker to make judgments about comfort and discomfort varied, with past contextual events and interpersonal and intrapersonal processes often influencing current actions. Some items of adaptive equipment necessitate precise application which appeared to cause some of the children and young people discomfort, yet the significant others appeared to unify an ethic of caring attentiveness in consideration of this technology. This study did not set out to make decisional theory explicit, but the three subdivisions of this section did emerge as possible important environmental influences on such processes

### ***Organisational conventions and family routines***

The significant others identified factors which influenced equipment use and responsiveness to situational events. Families spoke about daily routines, which at the start of each school day inevitably involved a predicted course of events in anticipation of their son or daughter's journey to the school or day centre followed several hours later by his or her return, often in a state of fatigue.

In the home context, fewer decision-making situations arose because parents at an earlier point in time had already made decisions about which items of equipment their son or daughter would use at certain times of the day. Some decisions were based on beliefs about its perceived comfort. The parents did not question the need for mobile seating devices and 'comfy' home chairs, and expressed preference for these items considered more necessary for child and family functioning. Items more easily abandoned in the home were those making care processes onerous or causing their son or daughter perceived distress. Only one family still had a standing device at home and only one used a night-time support system. There was parental appreciation of less restrictive home alternatives: the sofa, the floor, the bed and 'comfy' supportive chairs. Nonetheless, the therapists in this study involved in establishing the home management programmes had awareness of the influencing factors, which often restricted equipment use to weekends or even non-use, but still worked with the families to achieve prudent outcomes relevant to each child and family. Non-use is one means of avoiding equipment discomfort, but this

does not mean the individual can be discomfort free as prolonged postural positioning may still occur.

One factor not unique to equipment use but widely recognised as influencing family life and causing some stresses was increased time demands for caring routines. The families were happy for postural management tasks to be undertaken at the school or day centre, but often amended the postural management programme at home. Perhaps this was their way of coping with time consuming or emotionally distressing tasks. Maul and Singer (2009) refer to this action as a proactive effort or specific accommodation made by families to adapt positively to their child with disabilities by counterbalancing, the many competing and contradictory forces in their lives. Hassall, Rose and McDonald (2005) maintain that parents of children with an intellectual disability experience significantly higher levels of parenting stress than parents of non-disabled children, but employ various strategies to adapt successfully to the demands posed by the child. Gevir *et al.* (2006) subsequently investigated time use and found that mothers of children with disabilities were equally adept in finding the necessary resources to satisfactorily balance their use of time in comparison to mothers of children without disabilities. If families are able to balance the competing pressures the obligations of caring for a child or young person may be tiring but not always burdensome. Interestingly O'Brien (2004) reports a strong positive correlation between the frequency of routines and the importance of routines, with mothers' stress related to daily routines most evident when mothers had fewer planned days.

Whilst the use of postural management equipment is not signalled out as a separate source of parental stress in many studies, owing to possible sampling differences or classification under such terms as 'care giving demands', skeletal deformities were reported as burdensome by the parents in a study by Tadema and Vlaskamp (2009). Henderson, Skeleton and Rosenbaum (2008), would argue that assistive device technology does increase difficulty in the activity of care giving. Their study investigated parents' views on the current state of adaptive seating technology and report that over one hour of a parent's time per day is taken up transferring their son and daughter from seating systems. The findings in the current study suggest that families were largely supportive of interventions, which took place at school or the day centre, and happy for their continuation, which may support the notion of parent accommodations taking place (Maul and Singer, 2009), and other important caring tasks taking precedent over postural management.

### ***Home is home***

One further finding of noteworthy discussion, not based on decisions around restriction imposed by the equipment and fatigue (as discussed in the next section), is parental choice and a desire for their son or daughter to have 'time-out' at the end of the school day. These actions were often not spontaneous; rather they had become routine family practices. I interpreted time-out, either as freedom from any support, which saw a number of the children using the home sofa, the floor or even bed, whilst other families accepted supportive arm chairs. Information about recreational and leisure activities for children and young people with complex multiple disabilities is only in its infancy and likely complex due to their developmentally expected differences. (Law *et al.* 2006, p.342). In the current population informal recreation is likely to be more social than physical and choices families make to fit their needs, preferences, environment, culture, and lifestyle. Those families in the study with other children spoke about 'freedom' on the floor with their siblings.

Zabriskie and McCormack (2001, p.281) conducted a preliminary study to explore a model of family leisure functioning underpinned by family systems theory. They use the description by Klein and White (1996) stating families are goal directed dynamic interconnected systems that both affect and in consequence affected by their environment and by qualities within the family system itself. Their findings indicate that the model does provide viable theoretical argument within the framework to further test and understand the nature of family leisure relationships. Dodd *et al.* (2009) followed up some of these relationships among families that include children with developmental disabilities with findings suggestive of leisure involvement similar to traditional families. Whilst constraints limit the options available for the children and young people in this study, it appears feasible to suggest the family are making choices and trying to give their son and daughter some freedom. This finding gives further insight into needs of families.

### ***School and day centre routines***

Additional findings drew attention to routines within the educational or training environment of the children and young people; environments where professionals and support staff shared the common goal of working collaboratively with each other and with parents. The success of this venture sees the multidimensional needs of the children and young people addressed within an inclusive framework. Curriculum planning within special education or care planning within day care services indirectly

attended to the issue of prolonged positioning, thereby potentially influencing comfort and discomfort.

In the school and day centre settings, mobile adaptive seating is a much-needed environmental resource, a source of frustration when things go wrong. The current findings support the work of Tefler, Solomonidis and Spence (2010), who report on the dissatisfaction expressed by school staff members with regard to the reliability of these systems and the time it takes to obtain replacement systems. Equipment as such facilitates transitions, enabling inclusion into the life of the school; daily routines would be very difficult without such equipment. The children and young people do not use adaptive seating to enjoy the seat. Accepting the limitations imposed by their health condition, positioning has purpose: engagement with curriculum activities, access to the outdoor play areas, participation in school assemblies and all the other social interactions afforded within such establishments each day. Seldom during intense one to one interactions or social group interactions were any of the children and young people observed to be in a state of distress.

Adaptive equipment is a classroom resource and its use in such settings supplants perceived therapeutic status. The child or young person can be at ease within their environment. Ashdown and Darlington (2007) point out that the pedagogy for pupils with PMLD is continuing to develop, but states that building an inclusive curriculum remains essential if there is to be meaningful involvement of the pupils. Similar to the finding from the current study, these authors refer to multisensory teaching approaches, sensory learning environments, hydrotherapy, physiotherapy programmes and physical care routines. A seated position is not the position of choice for many of these activities. In consequence careful curriculum planning indirectly dictates that the child or young person's position to be changed if the curriculum is to be truly inclusive. This postural repositioning is not contradictory to the findings of Ryan *et al.* (2009) who found school personnel in spite of the barriers try to implement postural management or postural repositioning programmes.

With the potential for positional change to affect comfort indirectly, Telfer *et al.* (2010) reports on the average time spent by teaching staff members transferring children to and from their seating systems during the course of a day, estimated 1 hour 3 minutes for teaching staff. Whilst potentially reducing the time available for educational, therapeutic and social activities the activity itself brings about positional change and potentially enhances comfort through the relief it brings. Prolonged positioning can lead to discomfort, pressure sores, fatigue and pain, but it does



appear there is opportunity for relief from equipment use, and perhaps enhanced comfort outside of the therapy facilitated postural management programmes, with the most routine care event, personal hygiene, being one example.

### ***Acquired experience***

In addition to the organisational and routine conventions and the adept sharing of the decisional processes underpinning professional, parental and caregiver judgments, the significant others had to confront pressing decision-making situations when the child or young person presented with behavioural expressions deemed more negative. Sometimes decisions made were unilateral, other times shared, but not based on isolated decisions taken by people unfamiliar with the child or young person. They recalled many past events; the team and family had experience of the child or young person's responsiveness to equipment. Knowing their son or daughter, and knowing the child or young person were common statements made by the significant others, a finding supported by work of Abu-Saad and Harmers (1997) who highlighted knowledge and experience as one of the influences on the decision making process in the care of children in pain. In consideration of equipment discomfort, parents may be the only individuals to observe end of day fatigue.

Accepting the possibility of decision-making errors, this finding is reasonable. If, for example, the outcome from a distressing situational decision making lead to removal of the child or young person from the equipment followed by a subsequent state of ease, this may confirm decision-maker judgement that perhaps the equipment itself was causative. In the presence of negative behavioural expression without observable physical factors the reasoning process becomes more complex, but again the outcome of any judgement contributing over time to the contextual accumulation of decision maker experience. Both situations contribute to professional, carer and parental experience. Historically the tacit knowledge of practitioners appears more widely accepted than that of parents with an increasing number of studies giving consideration to perspectives from which practitioner knowledge is generated (McCree and Bulanda, 2010). On the contrary, no longer should parents struggle to have their voices heard, past undervaluing now forms the basis of current ideologies aimed at establishing enabling and empowering parent-professional relationships. Parents possess a wealth of information about their child as they witness behaviour in environments largely unavailable to professionals; this reinforces the importance of the current findings. Discourse from the parents, and

the educational and health professionals in his study reveal examples of collaborative partnerships that have sustained the test of time. The professionals in this study listened to the parents, certainly to avoid occurrences of equipment discomfort.

On the basis of this and additional observed phenomena it did appear that whilst the parents, educational and health team perspective of use varied they generally understood and held respect for what the other had to offer. Between the biomedical and educational language offered as justification for equipment use and repositioning by the health and educational teams, the influence of parents featured prominently, decisions appeared to be transparent and shared processes managed collaboratively. All seemingly tuned in to the need to take responsive action when a decision on removal from the equipment became necessary, sometimes the parent and the therapist; at other times the therapist and the educational staff or the educational staff and the parents.

### ***Attentive care***

Parental need to safeguard their son or daughter was manifest, and not an unexpected finding. However, for the therapists, postural intervention did not appear to be just about the rehabilitative or about preventative goals, and for the teachers teaching assistants not just about the implementation of skill acquisition programs; they appeared to care about the children and young people. A combination of subcategories came under this category as naturally the significant others all had different roles but their responsive action I interpreted as embedded within what MacLeod and McPherson (2007) describe as human connection and 'caring'.

Parental role as caregivers' links to attachment theory and allied research aids understanding of parent child relationships. Goldberg (1993) in Spangler (2001) explains attachment discourse proffered by Bowlby (1969) as a theory grounded in ideas from psychoanalysis and ethology which focuses on the parent's role as protector and provider of security. Ties of affection between caregiver and child have a biological basis best understood in an evolutionary context since survival of human young depends on adult care giving (Bowlby, 1969). The evolutionary component presupposes a genetic bias among infants to behave in ways, often-negative emotional expression or crying, that maintain and enhance proximity to the caregiver and elicit caregiver attention biasing adults to behave reciprocally (Spangler, 2001). Of relevance in the current context is the psychoanalytic component which emphasizes the caregiver's role in reducing physiological arousal,

due to the complimentary care giving system of the mother or father in order to gain their support and comfort for emotional regulation (Spangler, 2001).

The therapists were aware of the distress some items of equipment produced, but not driven to achieve only impairment related goals and alongside educational staff regularly removed the child or young person from the equipment in cases of uncertainty. When the child or young person was distressed, they tried to make him or her feel more secure and intuitively appeared to know the point where responsive action became necessary. This often involved sensible physical contact, not just the functional or professional touch experienced during transfers. The significant others, like the parents, appear to display empathy toward those in their care. If they felt it necessary to remove the distressed child or young person from the equipment, they did in a caring manner. Hewett (2007) argues for maximum quality basic care for all people who have high support needs and writes of professionals in education who work with people who have severe, or profound and multiple learning difficulties 'I mean they have chosen to come into this work, and then chosen to stay in it. This despite routinely dealing with every known form of human excreta, and perhaps also being regularly scratched, bitten, slapped, kicked, screamed at, head butted, my observation is that these members of staff love their young people in the widest and most wholesome sense of human spiritual love'. The personal and moral values of the supporting team emerge as influences in the decision-making processes following the appearance of more negative behavioural expressions suggestive of a distressed child. The professionals appeared not to abandon personal values when the child or young person was distressed; in these circumstances Van Hooft (2006) suggests something deep within a person comes to be expressed as moral action. Those with the everyday lived experience of supporting the child or young person as mentioned do not possess embodied knowledge but likely possess empathetic knowledge. This is characterized as knowledge derived from close association or emotionality's with others experiencing a particular event (Agincourt-Canning, 2005). In their relationships, they demonstrated empathy and human connection, helping the child or young person cope with their distress or discomfort.

Findings from empirical and theoretical literature on empathy give support to the interpretations I make about the disposition of staff working with the children and young people in the current study. For humans, empathy depends upon features of the incoming stimulus, observer knowledge and disposition (Goubert *et al.*, 2005). MacLeod and Mc Pherson (2007, p.1590) further explain the lifespan construct of attachment theory stating 'the way a person relates to another can be predicted by

their own experiences of care from infancy through their development', with those experiences contributing to 'the formation of models of care that are evidence in how individuals relate to others'. In the context of seeing people in discomfort, humans have the ability to perceive the experience and thus provide comfort on that basis. Referring to the works of Jackson (2005) and Jackson *et al.*, (2006), Campbell-Yeo, Latimer and Johnson (2008) describe the empathetic response as autonomic, independent of previously described attributes of experience, and involving identification of the incoming stimulus. This means prior experience and conscious association may mediate the degree of empathetic response, but the lack of prior experience does not preclude the occurrence of basic empathetic arousal. Referring to the work of Ikes (2003), these authors give further emphasis to its complexity stating that the empathetic response is a form of psychological inference in which observation, memory, knowledge and reasoning combine to yield insights into the thoughts and feelings of others. They also contend that non-verbal pain expressions are antecedents of empathy.

There was no explicit reference by the significant others to the use mindfulness, a cognitive behavioural strategy for alleviating psychological distress, in person with PMLD. However the study gives support to the evidence of Singh *et al.*, (2004) who found increasing the mindfulness of a carer can produce substantial increase in the levels of happiness in persons with PMLD.

### **Situational clues**

It is difficult to dismiss the physicality of adaptive equipment; a wheelchair, an adapted seat, a standing frame or sleep system are technologically and scientifically designed items, which locate and hold the human body in a certain position. The likelihood of depicting discomfort this way was not surprising. Antecedents of discomfort become the focus of discussion at the beginning of this section; although it has to be pointed out not all affective negative behaviours in the children and young people were attributable to these factors. Behavioural uneasiness, anxiety and distress as already discussed saw the appearance of similar communicative signals. A discussion of possible antecedents leading to comfort occupies the second part of this section.

### ***Antecedents of discomfort***

Some items of postural management equipment require additional accessories and securing straps. By design, some of the accessories function through the application

of mechanical forces, perceived necessary to minimise the effects of known secondary health conditions. The standing frame is one such item. Positioning of a child or young person in such an item is not possible without the use of securing straps and the selective positioning of these straps can provide for a prolonged stretch of musculoskeletal soft tissue.

Stretch induces a number of physiological processes including transient viscoelastic deformation and neural responses; this is sufficient to cause discomfort in individuals without intellectual disabilities (Folpp *et al.*, 2006). Physiotherapists perceive stretch to be desirable in preventing shortening of soft tissue structures, and regularly implement this technique. However, a systematic review by Katalanic *et al.* (2010) conclude the evidence for stretch as an intervention for treating contractures in person with neurological conditions remains inconclusive. Stretch may lead to apparent but not real changes in muscle extensibility; this primarily due to changes in a person's tolerance to an uncomfortable sensation (Folpp *et al.*, 2006; Ben *et al.*, 2005; Leong, 2002). Further research is necessary, but of importance is knowledge that an uncomfortable sensation, alongside structural and biochemical adaptations accompanies stretch of the tissues in healthy able-bodied individuals. This leaves little doubt that stretching has the potential to be uncomfortable in children and young people with severe and profound physical impairments who may already have existing secondary conditions. It is now widely acknowledged that individuals similar to those in the study feel pain (Hadden and von Baeyer, 2005). Individuals without intellectual impairment are able to give informed consent to such procedures, and perhaps they will persevere with a discomfort sensation if in the long term they foresee benefit (Folpp *et al.*, 2006). The child or young person with intellectual disabilities is different; without the capacity to understand the reasoning underpinning such procedures they cannot rationalise the contribution of short term discomfort to perceived longer term gains.

Stretching invariably precedes equipment use as therapists and direct support staff aim to achieve maximum length of tight structures before application. However, a number of staff and parents expressed views in this regard, all with suggestion of a pain or discomfort sensation. I also witnessed these facial grimaces during the preparatory stretch techniques. Literature concurs with these findings, Hadden and Von Bayer (2002) note that of the 67% of caregivers, who reported their child to have experienced pain in the previous month, 93 % reported assisted stretching as painful, with 58.1% experiencing pain during splint application. Bush *et al.* (2010) more recently carried out a systematic review of assisted standing for children with

cerebral palsy, concluding that the published scientific evidence to support the potential benefits of assisted standing is limited. The scant evidence only supports the use of standing aids for goals of achieving bone mineral density, altering muscle tone and improving hip joint development. Daniels *et al.* (2005; 2004) report the results of a qualitative investigation which highlight the advantages and potential limitations of designs and features of standing frames, and assessed their use and acceptability by users (children 8-14), therapists and carers. The children in their study were able to express views, the authors found that five of the children liked the colour and six liked the comfort. Two children disliked standing due to discomfort and knee pain. The children preferred the standing frames given to them during the trial. Six children said they would like to move around more in their regular frame and four said they would like to improve comfort of their own frame. Herman *et al.* (2007) sought to quantify weight bearing in nineteen children with cerebral palsy while they were using passive standers, five of whom had pelvic obliquity. They related variation to the inclination, type of device and the individual child as accounting for the wide variation of weight bearing. Comfort or discomfort was not under discussion, time within the standing frame ranged from 15 minutes to 675 minutes per week.

Discomfort from restrictive straps was another reported source of equipment discomfort. The physical nature of this is again difficult to dismiss. Within schools, and for transportation, health and safety is priority; straps help prevent falls from the equipment (Elford, Beail and Clarke, 2010; Chaves *et al.*, 2007). The use of physical restraints generate much controversy in the delivery of services for people with aggressive and destructive behaviour, with restraint more recently described by Elford, Beail and Clarke (2010) as 'a very fine line' in an attempt 'to strike a balance between right and wrong, safety and danger, humanity and dehumanising, and helping and harming'. On the contrary the use of physical accessories for users of postural management equipment has undergone little appraisal. Chaves *et al.* (2007) views lap belts and wheelchairs restraints as a subcategory of physical restraint, when the user is unable to do the latch. These authors found little available evidence to direct professionals on the appropriate use of wheelchair restraints and lap belts. One feature of current seat design is a 'tilt in space' facility; this being a well used design feature in the current study. This feature provides gravitational support to stabilize the upper body (Ding *et al.*, 2008), which may reduce the magnitude of loading beneath the positioning straps. The families of Susan, and Vikki certainly preferred the 'comfy' armchair, which had a similar feature.

Foot straps receive little attention in the literature, but when used appropriately in sitting can assist lower body stability (Lacoste, Therrien and Prince, 2009; Myhr and von Wendt, 1993); however, Bergen *et al.* (1990) in Kuchler O'Shea, Carlson and Ramsay (2006) state that in the presence of deformity of limited joint mobility forcing the foot into neutral alignment on the footrest may impose undesirable stresses. Kuchler O'Shea, Carlson and Ramsey (2006) caution against constraining the feet of individuals who are able to make postural adjustments during weight shifting and actively place their feet. In general, research into the foot position appears limited to its influence on tissue viability.

McDonald, Surtees, and Wirz (2007) report on the thoughts of parents and therapists regarding seating equipment. Using a questionnaire, respondents completed a question on comfort and discomfort; they were to identify times when the seating was particularly comfortable, and times it was uncomfortable. Position and time of day cause most discomfort. The authors report did include a qualitative comment from one parent, which suggested their child was uncomfortable when completely strapped. An isolated statement, but considered alongside the findings of the current study it appears parents prefer less restrictive alternatives. On the other hand, the discomfort arising from a personal sense of restriction could be emotional with release giving freedom and relief from the restrictions imposed by the equipment.

### ***Errors of positioning***

The study by McDonald, Surtees, and Wirz (2007) speaks of position as contributing to discomfort, and likewise the voice of one parent in the same study 'if she is not seated correctly, leans to one side' reinforces the challenge of positioning children and young people similar to those in the current study accurately in the equipment. Whilst errors of positioning were not common as the staff were mindful of exactness, times of occurrence contributed to the negativity of equipment use, with inexperience of caregivers and hurried application contributing. Inexperience arose infrequently; systems were in place to ensure that at the beginning of each school year, one member of staff rotated into the new class with the children. In the day centre, each key worker had back-up support. In addition, positioning needs were subject to review and addressed collaboratively at the beginning of each year. Unfortunately, there were times when supply staff had to step in at short notice. There was no reference to this as causative, but the existing team did not underestimate their learning curve in relation to the presence of a new child in their

class. Janson (2005, p.31) comments 'children whose hamstrings are stretched even by a little bit, tend to squirm, stretch and slouch by sliding their hips forward in order to relieve the muscle tightness and pain'. Accurate initial assessment should avoid this in seating, but this message reinforces the consequence if positioning errors occur. The report by Chaves *et al.* (2007) provides data on persons who have died or experienced physical complications from restraint usage, and whilst the study population differs from the population in the current study it should serve as a reminder of the consequence of improper use.

### ***Duration of equipment use***

McDonald, Surtees and Wirz (2007) report on the number of hours spent in a chair, with between 3 to 10 hours reported by parents in their study of 30 respondents. These figures did not include detail of single episode duration. The current study provided detail and also revealed how vigilant the significant others were in monitoring the occurrence of excess pressure and friction arising from the equipment. They were aware these risks could lead to pressure ulcer formation, although the incidence in this subgroup at the time of the study was rare. Nonetheless, the odd occurrences act as a reminder of the risk. The intention of postural repositioning programmes were to give each child and young person the opportunity to be out of the sitting position at least once during the school or day centre day, which appeared to be successful in managing the risk of pressure ulcer development. Whether this has an influence on discomfort is difficult to determine. Reenalda *et al.* (2009) found that non-disabled seated individuals made postural adjustments on average 7.8+/-5.2 times an hour, with a subsequent increase in tissue oxygen saturation occurring during each postural shift. The mechanisms that allow able-bodied individuals and wheelchair users without sensation to remain seated for several hours a day, or whilst travelling without developing pressure ulcers is due to regular postural adjustments and subsequent influx of fresh oxygenated blood and the removal of metabolic waste from the previously compressed region. However, the effects of pressure ulcer interventions, voluntary muscle contractions, pressure relief manoeuvres and subconscious positional change on sitting discomfort, have been overlooked (Solis *et al.*, 2010). In summary, the majority of the children although immobile in regard of ambulation and finite weight shifting potential, were when given the opportunity, not motionless. How, and if, this influences discomfort remains uncertain.



## ***Fatigue***

Across the decades certain accessories and types of equipment have had design limitations. Those reported to manufacturers becoming forerunners of change and ongoing developments in the field, especially limitations relating to adjustability, appearance, the interface surface, manoeuvrability and weight. The adapted seats of the children and young people in this study had some of the more modern design features. Yet even in the absence of design or positioning error, one cause of changing status reported as limiting or restricting duration of equipment use was tiredness and fatigue. Malone and Vogtle (2010) define fatigue as a subjective lack of physical and mental energy that interferes with usual activities. In the context of this study, this could account for changing bio behavioural alertness in some of the children and young people. However, as noted in the findings for Susan and Dominic, arousal and alertness in itself was challenging. This fatigue may be due to other factors; of some relevance is biomechanical fatigue, a decline of strength. This is described by Dobkin (2008), as a reduced ability of the muscles to produce force or power as routine use of muscle groups proceeds, regardless of whether the task is sustainable. If the degree of weakening is not profound masking of fatigue is possible; this however appears unlikely for some of the children and young people in the study due to diminished control of posture and movements. In field studies of comfort and discomfort in office workers, Helander and Zhang (1997) relate discomfort to biomechanics and fatigue, but argue that if the chair is of good design fatigue is due to the passage of time accumulated during the working day. The very nature of postural management equipment means it is personalised and adapted to each individual. Other than reporting of views on reduced tolerance levels and discomfort there was no further exploration gained in this study relating to biomechanics and fatigue. However well-designed the equipment, the bodies of the children and young people will likely remain subject to atypical biomechanical stresses due to their health condition so end of day sitting fatigue is a real possibility. As the findings suggest, this was addressed by removing the child or young person from the equipment.

## **Antecedents of comfort**

### ***Avoidance***

Parents of children with disabilities cope with stressors in different ways (Jobe, Gidden and Billings, 2006); some use problem-solving strategies (planned problem solving, confrontive coping and seeking social support) in comparison to emotion-

focused strategies (escape avoidance and distancing). Although exploration of these strategies was outside the scope of this study, avoidance of a discomfort occurring would appear to be more of a problem solving strategy on behalf of the parents, as there was no instance of equipment abandonment in totality. Research involving parents of children with disabilities suggests positive associations between the use of certain items of equipment, particularly adaptive seating, and meaningful positive impact on child and family life (Ryan *et al.*, 2009; Ostensjo, Carlberg and Vollestad, 2005). Nonetheless such equipment is not devoid of limitations, and teams of researchers have strived to investigate barriers to successful implementation (Hutton and Coxon, 2011; Tefler, Solomonidis and Spence, 2010; Huang, Sugden and Beveridge, 2009; 2008). Barriers documented include issues surrounding assessment and planning, resources, training, environmental barriers, servicing and renewal of the equipment and staff attitudes. A number were documented in this study. Few studies, however, focus on the impact of technology on the caregiver (Skeleton and Rosenbaum, 2008). Views between interested parties about the benefits of equipment may vary, yet the area where consistency is found relates to the importance of comfort as an outcome (Tefler, Solomonidis and Spence, 2010; McDonald, Surtees and Wirz, 2003). Rarely at school or in a day centre will a staff member have to cope with a distressed child or young person alone when an eventful situation arises? At home, the situation is different, and the parent in isolation may make a decision based on best outcome for themselves and child.

### ***Posturally managed position***

The therapists perceive the preciseness of the postural position to be important in the avoidance of discomfort, and with duration managed an antecedent of physical comfort. Daytime and night-time postural positioning programmes have developed in recent decades to address neuromuscular impairments of body function.

However, the manner of equipment use in this study supports decisional frameworks not restricted to only those with a body function component, especially the continuous postural management programmes referred to in Gough (2009).

Nonetheless, due to the complexity of body disturbances in this population these components do feature in the findings, and remain of concern for parents. Telfer, Solomonidis and Spence (2010) more recently found that parents do consider prevention of deformity amongst the most highly ranked functions of adaptive seating.

Selective and time limited use of equipment may reduce excessive tissue loading. Positioning the body within a personalised item can also reduce tissue loading, and for these children and young people limited positioning options are available. Without the use of adaptive equipment, the unsupported lying position becomes a real possibility, and this increases the risk of secondary complications due to poor positioning, as identified in classic papers from the last century (Fulford and Brown, 1976; Asher, 1947).

The current findings also saw the children and young people engaged in tasks meaningful to them, adopting positions at odds with postural management. They were safe in these positions. Posturally managed standing was the exception for some of the children and young people casting doubt over benefit if comfort is a desirable outcome. A study by Breau *et al.* (2007) who found that children with developmental disabilities perform fewer adaptive skills when pain is present gives some support to these findings.

### ***Movement***

In accounting for discomfort avoidance and or its relief, some observations are noteworthy. The low reporting of pressure sores could suggest the postural repositioning programmes, the interface surfaces and attentive care giving were effective. Those pressure sores reported in the current study were linked to a hospital admission, or imposed restriction of movement following surgical a procedure. Equipment provides a supportive, not restrictive, micro-environment for the child or young person and some movement within the equipment was observed. This perhaps having some role to play in the avoidance of tissue overload. A comforting response may also occur through movement, even if the movement patterns are uncharacteristic and insufficient for independent postural re-positioning or transfers. Movement opportunities within the equipment also occurred following mindful and selected release of restrictive straps. A number of the children and young people gained pleasure from the freedom of movement out of the equipment.

Movement itself is a critical aspect of life, and several theories of motor control exist that help explain development and altered movement patterns (Shumway-Cook and Woollacott, 2007, p.4). Nonetheless even the altered, and albeit variable patterns the children and young people in this study (spontaneous, stereotypical, voluntary, restless, large range, small range) may have some importance in the avoidance of discomfort. These movement patterns may produce a tissue response, similar to fidgeting, which is the typical response to a discomforting sensation due to tissue

occlusion as a consequence of abnormal tissue loading. Children and young people, similar to those in the current study, perceive pain (Bodfish *et al.* 2006). Therefore it appears feasible to suggest that the children and young people respond to tissue overload with a movement, as the sensory /perceptual system processes information about the state of their body tissues.

Three of the individuals who the significant others reported as indicating preference of sitting over standing, appeared to make some postural adjustments in sitting. Two of the school pupils whose cognitive difficulties surpassed reduced postural control status in sitting did not cope well with extended periods secured in one position becoming fidgety with the passage of time. Although movement control was a challenge for the children and young people opportunity for its occurrence whilst in the equipment appears more comforting than discomforting.

### ***Postural repositioning***

Responsibility for relief and avoidance of discomfort for the children and young people in this study meant others acted in a manner they considered appropriate. In nursing, theorists would define these actions by vigilant caregivers as 'comfort measures' (Siefert, 2002; Kolcaba, 1991). Postural repositioning in the study was perhaps the most common antecedent of comfort. I make the distinction between this and postural management using adaptive equipment. Postural repositioning includes a change of position; this could be scheduled and unscheduled repositioning with pre-planned curriculum activities and personal hygiene positioning changes all contributing. A seated position is not the position of choice for many of these activities. In consequence careful curriculum planning indirectly dictates that the child's or young person's position be changed if the curriculum is to be truly inclusive.

### ***Aesthetics***

Without a child or young person, items of seating or postural management equipment become detached objects, but as an inanimate object they can still provide an aesthetic pleasing or displeasing experience for the caregiver. Judgments by the caregivers were made about appearance, and the words used to describe the shape, form and texture of the equipment. More aesthetically pleasing items were judged comfortable, others less pleasing on the eye. Standing equipment was not subject to the same scrutiny; perhaps participants sensed that unlike adapted seating use would be more restricted. More than a decade ago,

Helander and Zhang (1997) related aesthetics as contributing primarily to comfort as opposed to discomfort judgments; their work however related to the design of chairs for the workplace. The participants in their study could however give their own subjective judgments. In the current study, vision processing was used to perceive its functionality and the physicality of a comfort discomfort dimension for the child or young person within the seat. Appearance, for many participants, remained important in terms of judging its comfort. For the educational staff in the classroom and parents, equipment was compared, and aesthetics was used for this comparison. Equipment had become part of family life, with the parents also becoming users of the equipment. Several of the parents and some teaching support staff spoke about the changing design of equipment over the years; they had become more discerning.

The technical, material, inanimate object locates the person in a secure position, but the perceived child friendly item has to look comfortable even before contact is made with the body; rigid, unpadded, inflexible equipment as the findings suggest portray undesirable images. Such images may lead to restricted use or abandonment. Buggy-to-wheelchair progression was the topic of a small study undertaken by Shahid (2004); the findings reveal the conflicting views held by parents and health professionals about this transition stage. For parents the wheelchair made their child's disability more obvious and difficult to cope. Despite the many improvements in design technology, current findings reveal the notion of aesthetics remains an important contributory factor.

### **Comfort and discomfort: connected and independent**

.....comfort freed all patients to be all that they could be at the time

Paterson and Zderad (1976) in Kolcaba (2003, p.7)

The achievement of comfort and the avoidance of discomfort for the children and young people in this study was embedded into everyday routine events, with the significant others having a mediating role in this process. In this final section of the discussion, I explore the consequence of the actions taken by the significant others as these appear critical to achieving an understanding of the more desirable outcome-comfort.

## **Relief**

In the current study, it appears feasible to suggest a number of the aforementioned physical discomforts would provoke physiological, microcirculatory and neural, responses, including sensory self-awareness of the discomfort. The parents, therapists, teachers and classroom support staff had an acute awareness of these sources of physical discomfort, and on most occasions the task of meeting comfort needs did not go amiss. An action response, by the significant others, followed attribution of meaning to the expressive behaviours of the child or young person. Often this involved removal from the equipment, a solution perceived to bring about relief.

Reactive hyperaemia is the healthy counteraction to occlusion (Collins *et al*, 2002), which may bring about this relief. Some valuable studies support a significant correlation between subjective ratings of comfort, reactive hyperaemia (Goosens, 2009) and causative sources of physical discomforts for wheelchair users (Stockton, Gebhardt, and Clark, 2009; Crane, *et al.*, 2004). The presence of a physical discomfort gives it antecedent status in terms of comfort, meaning a discomfort is necessary before 'relief' becomes possible (Kolcaba, 2003, 2001 and 1991). 'Relief' is one of the three types of comfort embedded into Kolcaba's taxonomic structure of comfort. In health care environments, relief from discomfort is a major focus of care, and causative physical symptoms must be alleviated. In an ethnographic study of comfort on wards for older people discomfort was found to be of prime importance, with relief from sitting mentioned by the residents (Tutton and Seers, 2004). In the current context this may bring about a state of ease, but is the child comfortable? There were numerous examples of the children and young people functioning well in the equipment without a pre-identified source of physical distress, which reinforces the multidimensional nature of comfort.

## **Functionality**

A number of events described in the findings illustrate how intent and purpose underpinned the use of adaptive equipment. In the school setting, an activity, a lesson, a play or free time activity was often scheduled. Aside individualised goals or targets; for example the operation of a switch during circle time, purposeful use also included facilitating access to peers, alongside other opportunities for social interactions. Equipment use varied. In the environments where equipment was accepted as part of everyday living the children and young people appeared at ease because the adaptive element catered for individual need and responsiveness. The

children and young people could be at ease in the equipment without the precondition of discomfort. In school there was a recognised preference for type of equipment, in favour of adaptive seating; its use appearing to have social, emotional and educational benefits for the child, simply by enabling access and inclusion. There were many occasions during the course of this study where the participants spoke of children and young people functioning well in the equipment, with the context and situational events likely contributing to stable behavioural expressions, or happy as opposed to unhappy expressions. The absence of negative non-verbal behaviour alongside the absence of an observed discomfort antecedent would suggest, either a state of no awareness at all of a feeling, or what is also described by Kolcaba (2003) as another type of comfort an 'at ease' state.

The current contextual findings supports the view, long held in the field of ergonomic workplace seating, (Hertzberg, 1958 in Zacharkow, 1988, p.10; Branton, 1966) that comfort is not simply the absence of discomfort but a distinct concept in its own right. Comfort was influenced by other factors. Zhang *et al.* (1996) and Helander and Zhang (1997) speak of well-being and relaxation. Subjective well-being was indescribable for the children and young people in this study, but those significant others who knew their likes and dislikes did offer opinion. A content or at ease status was achievable using most items of equipment. The role of the significant others in addressing overall comfort needs was important; they could position and reposition the child or young person, as necessary, but they also held the capacity to influence each situational event within the inclusive environments.

### ***Distraction***

Meeting the needs of this group of children and young people appeared to require more than just the physical placement in the equipment. Time, according to Maher *et al.* (2010), is rarely at a premium in special school settings; yet the children and young people could be at ease, and perhaps maintained at ease longer, with human made changes to the environment.

I mean you could put her in and sit her in front of the telly and she would watch the telly but that wouldn't last long. Her concentration is not great so the need to entertain while she was in the chair was there. You couldn't just sort of stick her there and think oh well she's sat in the seat, she would be quite happy, that just didn't work (Pi9:7).

Even those with pre-intentional communicative forms appeared to benefit. One transforming change mentioned, as applicable for a number of the children, was the

use of standing devices in school assembly, as opposed to the classroom. This whole school event was a happy experience; there was lots of singing, rewards were distributed and the children praised. Some of the children would grimace with the preparatory stretches necessary for postural positioning within the equipment, but in assembly they appeared distracted. The size of the school hall accommodated these larger items of equipment. This level of planning is perhaps indicative of what might be achievable for those children and young people for whom postural management is considered imperative, or for those for whom postural positioning is desirable, but within an inclusive environment. This distraction perhaps equating to the type of comfort Kolcaba (2005, p.15) refers to as transcendence, or the state where one can rise above problems or pain.

## **Concluding discussion**

In this final section, my aim is to draw the findings together into general discussion. Equipment, as explained, provides a microenvironment for the child or young person and the impact of context on both comfort and discomfort has been described. Grave and Walsh (1998, p.11) speak of contexts as relational and not static, meaning 'they shape and are shaped by individuals, tools, resources, intentions, and ideas in a particular setting, within a particular time'. This aptly helps explain why the children and young people can be both comfortable and uncomfortable in the same item of equipment owing to their requirements for a communicative partner and caregiver. Significant others in similar settings must therefore have a particularly influencing role over outcome. In the current study, these individuals were all directly or indirectly accountable for transfer of the child or young person in and out of the equipment, and thereafter manner and duration of use. They influenced positioning within the micro-environment of the equipment but held responsibility for manipulating the more global external environment. The more desirable outcome is a responsive contented child or young person. Unfortunately, confronted with the inanimate nature of the adaptive technology, some applications can cause discomfort and fail to achieve the status of a positive environmental asset. Retaining supports used within an item of equipment, for example, may cause physical discomfort; however, there may also be emotion associated with the restriction which may itself be distressing. Release gives freedom and relief from the restrictions imposed by the equipment. In the current contexts, communicative partners prompt action, but the question of whether equipment related discomforts



can be reduced or minimised and comfort achieved appears to come down to attentive and mindful caregiving acts.

In a comparative survey parents and therapists expressed views about adaptive seating (McDonald, Surtees and Wirz, 2007). One question asked the participants to identify times when the children were particularly comfortable in their chair. Interestingly, the parents felt that environmental and personal factors, activity and participation contributed to their child's comfort, whilst the therapists in the study perceived attention to the physical body would enhance comfort, followed by the environmental and personal factors mentioned by the parents. This was a valuable study as it urges practitioners to pay particular attention to all domains within the ICF not just evidence for the efficacy of postural management (body structures and function), which is currently still limited. It appears important to remember that comfort is an objective that crosses all domains. If the presence of a physical discomfort causes a body function disturbance, relief can be an interventional aim. Nonetheless, if the purpose of using adaptive equipment is to promote improved functioning and participation antecedents of discomfort still need to be minimised. To address comfort the significant others must consider the microenvironment the equipment provides and the environment where it will be used.

## **CHAPTER 11**

### **REFLECTIONS ON THE PROCESS OF THE RESEARCH**

#### **Overview of the chapter**

Advancement of contextual knowledge about the comfort of adaptive equipment involved, on my part, personal and professional commitment. Central to this was my role; I could be an 'insider', taking an emic perspective, but held researcher responsibility to analyse critically and impartially from the outside (Bray, 2008, p.307). Acknowledging my presence from the outset, my aim was to achieve transparency by engaging in a reflexive sense with the methodology and the analytical processes leading to subsequent conclusions. Some complexities relating to my role in the research I recognized at the outset, and as I reconsidered aspirations of giving 'voice' to the children and young people more surfaced. For this intent I cannot claim assurance, I did not intend to speak for the children and young people, but neither could they speak for themselves. I observed but did not experience the source of their distress, although I had in the past experienced sitting discomfort. I was, however, able to illuminate the situational experiences, satisfying or otherwise as the children and young people used their adaptive equipment. In this chapter, I begin with some reflections on self, followed by a short reflective overview of ethical issues. Next, I review the philosophical and theoretical assumptions underpinning the methodology, reviewing the decision-making processes I engaged with during the research process. I then proceed to unite the strategies used for promoting quality in the study.

#### **Reflection on self**

I engaged in a complex and delicate process of exploration and negotiation, and it would be epistemologically wrong to deny my role in the research. Reflexivity was used as a concept to enhance transparency (Flick, 2007). Reflections constantly fluctuated. Nonetheless, I concede not every thought was accounted for, and that some aspects of self were not fully explicated until later analysis of my reflective diary. Other thoughts likely remained outside my consciousness.

A professional bias was evident in the topic selection. Throughout I was forthright about subjectivity and notions that the significant others and myself as part of an 'inter-subjective' relationship would share a lens through which we could interpret comfort and discomfort. On-going reflections often challenged the ideologies underpinning the established research strategy; these mainly related to the

aspirations I had set myself of giving 'voice' to the children and young people in the research. Apposite examples of this as a challenging predicament were recorded in my research diary, particularly for those communicators who functioned pre-linguistically. I was using ethnographic methods but could not use a participatory methodology, favoured in learning difficulty research, with the children and young people in the main study (Chappell, 2000), and my analysis was not intended to be a critical theoretical analysis. How could I resolve this dilemma? Expanded reflexivity of self, as I now explain, proved to be a process that both challenged and clarified my assumptions; it helped re-position some of the dilemmas I experienced about 'giving' voice to the children and young people. Cutcliffe (2003, p136) speaks of creative, interpretative, and tacit knowledge processes influencing the qualitative inquiry. Thus, in my efforts to 'give voice', I had to take some risks and explore thoughts more boldly as the study progressed. Empathetic intuition, which likely influenced the illustrative outcomes, was my solution to giving the children and young people some voice.

The focus of this research originated from a practice-based critical incident. 'Fear of unnoticed intrusive bodily sensations' was the phrase documented in my research proposal; words which suggest an empathetic influence. I had considered the emotional expressivity of the children and young people, and empathy had entered into my discussion of attentive care giving. However, in hindsight, I had not examined the role and legitimacy of my own emotions in response to the incident or the occasions I witnessed distress. Denzin (2007, p.161) refers to 'enacted emotionality' as an inter-subjective process that places the person in the presence of another and involves the articulation and expression of emotional definitions of self and the situation. I could not feel what the children and young people were feeling, but I cared sufficiently about what they were feeling to instigate the research. Sobel (2008) argues that whilst empathy is difficult to define and difficult to recognise it refers to an ability to discern both cognitively and emotionally what another person is thinking and feeling, but not necessarily to feel what they are feeling. The reports in my reflective diary would, as suggested by Cutcliffe (2003, p.140), not just be a report of my interpretations, but a report of the participant's world as the researcher has experienced it through empathic and transferential processes.

The words of Hoffman (2000) reminded me of who I was at the beginning of this research

.....an observer may feel empathetically motivated to help someone in distress, but he may in addition feel obligated to help because he is a caring person who uphold the principles of caring. This activation of a caring principle and the addition of one "self " (the kind of person one is or wishes to be) should add power to one's situationally induced empathetic distress (Hoffman 2000, p.225).

The majority of my encounters with the children and young people were observational, as opposed to participatory. However, guided by the humanistic insights of Denzin (2007), Van Hooft (2006) and Hoffman (2000) and through my own meaning making I grasped the inter-subjectivity between myself and the children and young people and human concern to have their situation made explicit. Nonetheless, dilemmas relating to my role were a concern even though I used particular strategies to ensure there was synergy between research questions, data gathering and interpretations. Drawing from the advice of Mason (2002), I tried to focus my efforts meaningfully and strategically on the research itself, avoiding unbounded introspection.

### **Reflections on the ethics of the research**

Practical wisdom, regulatory approval processes and ongoing thoughtful 'process-principle' deliberations throughout the study gave some reassurance that the research was ethically sound. Yet in offering some pertinent examples of deliberations, particularly those arising because of conflict between quality expectations and ethical concerns, these decisions may be open to challenge. One apt example includes observation of the children and young people and the decision made, prior to the ethics review board, to only pursue this method in the school or day centre. Observations in the home I felt would invade the privacy of family life. This meant I would have no formal observation of family life interactions. Virtue ethics are concerned with deliberations over what makes a good person, not with what makes a right action, and Gallagher (2009) contends that in opposition to someone who is compassionate, caring and empathetic, a good researcher could be someone who strives to be objective and unbiased. Based on rigour alone my decision is questionable. Another example, I switched off the video during all personal hygiene tasks, and because I was not a personal assistant did not observe this task which involved a transfer, from the child or young person's adaptive seating equipment to a changing table. I thereby missing opportunity to gather valuable data. I tried to address both deliberations using method triangulation and the sampling strategy meant I felt reasonably confident the beliefs of the significant

others would help me to construct the reality of equipment comfort and discomfort and account for missing information. This group of individuals lived and experienced everyday life with the children and young people and as such were dependable witnesses to those events I deemed inappropriate to observe. In many respects, my role as a researcher was in direct conflict with my relationship centred approach to practice. In regard of governing ethics, I had accepted a role as a participant observer, which for the pre-intentional communicators was largely observational. I did not see this role as having a hierarchical stance, but acknowledge exploitation in research can become an issue if researchers use superior power to achieve objectives at real cost to those they are studying (Murphy and Dingwall, 2007). Throughout the research I had to be aware of the responsive signals to my presence from the children and young people as this takes the form of assent, on reflection I felt the decisions made were in keeping with this expectation.

Informed consent and assent were discussed in chapter 6, alongside issues of anonymity and confidentiality; however, on reflection additional issues emerge. I had six variations of the informed consent forms, all designed and subject to scrutiny, and sets of principles were systematically followed. Yet ethical challenges still existed due to the nature of school-based/day centre case research. This type of research makes it difficult to ensure data remains non-attributable as my overt fieldwork would likely make the identity of the children, young people and significant others explicit to other employees who were not part of the study. I attempted to overcome this within the organisations by initial discussions with the gatekeepers, and again in open conversation with others who expressed interest in the research, although I divulged no case study information even when directly asked.

### **Reflections on the theoretical and philosophical framework**

At the outset, due to the severe and profound nature of children and young people's learning and communication difficulties, I sensed the need to place the research strategy within a theoretical tradition, which was broadly interpretive. Emphasis could then be given to context as a basis for enhanced understanding of comfort and discomfort. Stake (2010, p.36) reminds us that all research requires interpretations, but interpretive research he states relies on 'observers defining and redefining the meanings of what they see and hear' I envisaged the contextual reality would be more knowable to the significant others who regularly position and reposition the children and young people. Guided by an emic epistemology, which meant entering their world of purpose, meaning and beliefs, I gave explanation to

the behaviours of the children and young people, and the underpinning practice of significant others. A holistic analysis of real life understandings of comfort and discomfort was the product.

I did not fully explicate empathetic inter-subjectivity at the proposal stage, yet I sensed the presence of an emancipatory element 'fear of unnoticed intrusive bodily sensations'. Accordingly, if I had taken a critical perspective, prominent in emancipatory disability research (Oliver, 2002), the research might have been very different. Critical qualitative research requires researchers to relate discourses to underlying social structures, and the allure of this approach is the challenge to oppressive practice ways of analysing the situation of people with learning difficulties. I held experiential knowledge of the 'lived world' of similar children and young people before the era of adaptive seating. With beginnings founded in biomedicine, adaptive wheelchair seating had already afforded the possibility for people with profound and severe learning and physical difficulties to leave the authoritarian confines of institutional life and access the wider community (Watson and Woods 2005). Nonetheless this perspective could have provided a means to critically reflect on current service provider encounters between the children, the young people and the significant others. Burbank and Martins (2010, p.33) contend that a critical perspective is based on a critical realist ontology, appealing because it holds that there is reality 'out there'. This perspective partially supported my belief that prolonged restrained positioning might cause discomfort; however because observation is always value laden, and coloured by the views of the observer, reality may never be completely known. Therefore, on reflection, this ontology might have had an underpinning influence in the study. Nonetheless, prior to taking a macro perspective on the situation I felt there were micro level processes to consider first, due to the diminished contextual understanding of adaptive equipment comfort in this population. Concern was about the practical matters of equipment use.

The theoretical assumptions were therefore more traditional, but with a focus on interpretation of individual, organisational and cultural behaviours, in order to interpret the comfort needs of the children and young people when using the equipment. The decisions made at key points had a major impact on the evolving process, but they could have been other ones. My thesis would have been different if I had made the decision to focus only on the one concept, that of discomfort. I held propositional and experiential understandings about the possibility of a cause effect relationship, between the physicality of tissue loading and the experience of discomfort. I could have set hypotheses related to possible causative factors

deductively derived from theory and previous knowledge. Perceiving discomfort as pain would also have opened up opportunity to use validated pain measures. However, the current validated behavioural indicators of acute pain did not have situational transferability to the identification of equipment discomfort and there was comfort to consider, the more desirable state for humans. Likewise, if I had made the decision to only focus on comfort the thesis may have been different. As part of the literature review I came across analyses of comfort in nursing, a topic with numerous references to comfort as a nursing process.

Subsequent exploration of the literature during the analysis substantiated a number of the procedural actions taken by the significant others, which extended contextual meaning of both comfort and discomfort in the findings. Had I focused the research on procedural actions from the outset this potentially might have transferred ownership of the experience away from the recipients to the significant others. However, with no decisive literature linking adaptive equipment to comfort and discomfort the experiential position I adopted of necessity allowed the research questions, arising from a practice related critical incident, to develop and the findings to unfold. A focus on the two concepts (comfort and discomfort) may have given breadth at the expense of depth. Negative case analysis (Robson, 2011) is an important means of countering researcher bias, and I devoted time and attention to reflecting on instances, which disconfirmed initial and developing suppositions. For example, early in the research, I observed postural repositioning to be occurring regularly and had to consider the possibility that the children and young people might not use the equipment long enough to experience discomfort. I held reservations about the research agenda; however, because my intent was to focus also on comfort so these suppositions likely became more intricate.

In explicating the epistemological lens, I placed particular emphasis on knowledge development occurring out of everyday practice. Yet, it was not until I began to gather data did the implication of context spiral. I perceived the interest in equipment was isolating out other important daily practices but not the personal and environmental factors influencing the situational contexts. The qualitative research methodology enabled exploration of daily practices, expressive behaviours suggestive of comfort and discomfort, and the beliefs of the significant others about processes and outcomes of using equipment, within family and community settings.

## **Reflections on the sample**

To address the research questions, the sampling strategy was purposive and took into account the previously conceptualized framework. However, I had to recruit through gatekeepers to access the sample. This meant I had to specify the type of cases needed to allow for elaboration or refinement of emerging categories during the analysis. I draw from Charmaz (2006) who argues that this type of sampling is not a search for the negative properties of cases, but allows for them coming into the sample. I saw these distinctive categories coming into my analysis early. Whilst expecting individualism from the outset, I had specifically not categorized the movement dysfunction of the sample, perceiving spasticity to be the more common presentation. However, the first child moved too much, re-defining these early assumptions of mine.

The health, educational and social care needs of the thirteen children and young people in this study were distinct, but they all had a requirement for functional seating and wheeled mobility, without which the range of opportunities available would be severely restricted. At the outset I envisaged my sample to include a greater number of children with cerebral palsy and spasticity; this was not the case as my sample included those with dyskinetic cerebral palsy and those with other neurodevelopmental conditions. This apparent diversity did prompt me to include two more children and two young people in the research, but on reflection, perhaps I was mistakenly searching too early for presumptions rather than recognising uniqueness. Later reflections guided me to search for negative instances within each case, which would disconfirm my presumptions; on balance, the use of adaptive equipment was the cohesive link irrespective of the nature of the neurodevelopmental condition.

The sample was recruited through gatekeepers, the significant others through case attachment. This was because at the time of the study I had no direct access to the research sites. The possibility of gatekeepers biasing the sample should be a concern (Stoneman, 2007). With only one LEA and NHS trust overseeing the research, this selectively reduced the sample population who fulfilled the inclusion criteria. In the event, the numbers were sufficient for purposeful sampling and allowed maximum variation, thus serving to increase confidence in the conclusions. Recruitment included low-income families, single parent families and other families with less involvement with the school and therapy services. One of the low-income families agreed to participate, but did not return the signed consent forms. The



school had experienced similar difficulties with official documentation. The significant others with responsibility for behavioural interpretations had to know the child or young person really well. The case study strategy was a means to achieve this. Except for the family unit, some options remained open. Group selection of the team member within the classroom as to who fulfilled the role of the 'significant other' was an example. This meant on occasion, I interviewed the classroom teacher, other times the classroom support worker. The teachers had a greater role in classroom management, with likely responsibility for initiating policy initiatives, which might affect daily routines. However, there was evidence of both addressing care needs, and I did not perceive this to be a disadvantage. The teachers I interviewed individually. On three occasions, there was more than one familial support worker and I agreed to their request for a joint interview.

In the two LEA schools, when the pupils transferred into a new school year, one teaching assistant was usually included in the changeover; this meant there was continuity and enhanced ability to 'know the child or young person'. Obligated to retain the boundaries I set, case study design left little scope for flexibility. This did generate process issues. For example, sickness of a child meant that I might have interviewed the parent and proceeded with all the ethical arrangements for accessing the classroom, but if the child was then absent toward the end of the school year postponement of the observations and renegotiation of access with a new class teacher became necessary. Staff sickness also meant procedural delays, and on one occasion long-term sickness prevented member checking of the data. These difficulties and the timeframe involved meant it was not always possible to complete the process of data collection for some cases before commencing the next case. All participants were nominated by a gatekeeper, this potentially biasing the sample. It is however worthy of note that in the period of data gathering I saw no other children in the schools who would have fulfilled the criteria.

### **Reflections on the processes used for gathering data**

On reflection, I still support my decision to use multiple methods to gather data in the naturalistic setting. Case study design enabled inclusion of ethnographic approaches in contrast to those based only on language, although I might have had second thoughts if I had come across the following description of a classroom (Smile and Kayne, 1997 in Stoneman, 2007, p.40) 'a swarming dynamic system of interrelated phenomena'. Observational data collection periods were thwarted with challenges; ethics, disruptions, uncertainty, and distractions to name but a few.

Tenacity brought rewards and resolve with knowledge that my efforts offered opportunity for triangulation, helping to account for incomplete data. For example, as mentioned above, member checking was not complete for every respondent; alongside the teacher on long-term sick, another took overseas secondment, and one parent respondent moved out of the area. Interestingly, I found the respondents more enthusiastic about member checking the visual material from the video sequences, than the textual transcriptions. Possibly this activity promoted greater respondent reflection.

Ethical uncertainties, at the proposal stage, steered me away from an ethnographic approach in the special school setting. Spending more time in the field helps reduce any reactivity and respondent bias (Robson, 2011), and time was a limiting factor in the current study. However, if I had requested an extended observation period, uncertainty remains over gaining initial access. In the event I had negotiated regulatory requirements and I felt obliged to fulfil them. I did sense reactivity from some staff in the day centre; for example, they were very eager for me to attend on a day Philip used the tilt table, this was not something I specified in advance. However, in school, the curriculum day was easily identifiable from wall timetables, so reacting to my presence and changing activities would have altered the situation for other children in the class. In retrospect, if I had not interviewed the families I think my developing suppositions would have been different, and therefore I remain supportive of the methodological choices made. I felt the design implemented gained strength from parental involvement.

One of the main issues in data collection concerns the impact of the single researcher on the process, particularly with regard to bias. I had not worked as a practitioner in the geographic location of the current study and current employment status as a hybrid practitioner had detached me some years earlier from the service provision aspect of adaptive equipment. I therefore had to make every effort to be as rigorous and unbiased as possible in the collection of data, engaging in a reflexive process contributed to this.

### **Reflecting on the process of the analysis**

In chapter 9, I used a variety of formats to describe the analytical process in detail, aiming to demonstrate transparency. However, as the children and young people could not validate my interpretations I could only ever aim to offer an illustration of the two concepts. Use of two chapters to present the findings meant I retained allegiance to the 'individual', identifying themes for each case in order to further

knowledge of equipment comfort and discomfort. The thematic cross case analysis offered enhanced opportunity to give meaning to the collective findings, and putting these together enabled me to see comfort more clearly. Although case uniqueness was sometimes lost as all cases were not equally represented in each subcategory. A willingness to explore other avenues likely accounts for the diversity of subcategories.

A key feature arising in the analysis was the need to develop my own understandings related to particular concepts in this field of study. Behavioural research literature subsequently became useful in extending my findings into meaningful perspectives; without this those offered would have less meaning, for example interpretations of contentment, happiness and unhappiness. An example of this was the existing body of literature on behavioural expressions and communicative interactions. In hindsight, with this breadth of understanding at the beginning my interpretation of the behaviours may have had more focus. Corbin and Strauss (2008, p.37) suggest familiarity with relevant literature can enhance sensitivity to subtle nuances in the data; because I was less familiar with this literature at the outset this meant I did not impose behavioural concepts on the data. Reviewing this literature later in the research definitely affected the way I viewed and became sensitised to the findings, particularly my interpretations about comfort which at an earlier point in the analysis focused mainly on the antecedents of discomfort. Naively I had used the words happy, content and unhappy in the interviews, but simply to avoid biasing the experiences of the interviewees by overuse of the terms discomfort and comfort. I subsequently came to value later found indices of happiness (Petry and Maes, 2006), which helped extend and confirm the findings into meaningful perspectives.

### **Reflections on the quality of this study**

Issues of quality are of great concern. Flick (2007, p8) argues that it is unethical to do qualitative research if little consideration is given to quality; however, diverse standards exist. From the outset, I set out to have my findings trusted because of my aspirations to gain disciplinary acceptance and achieve the values I set as regards informing practice. Nevertheless, in the words of Robson (2011, p.14) I could not leave humanity behind when doing the research. Therefore I aimed to achieve quality by carrying out the research systematically, sceptically and ethically. I did not set out to produce statistically significant generalizable findings; contextual conclusions evolved from gathering rich and varied information, which emphasised

the complex multidimensional situational nature of comfort. Transferability of the results to those functioning in different settings rests with others, particularly those working in this specialist field who can critically review the quality strategies used and determine the relevance of its conclusion to their particular situation.

Description of data gathering was explicit; for example, I hold for scrutiny the complete transcription of all interviews, the videos, and copies of all correspondence including gatekeeper access, information and consent letters, appointment letters, member checking, the NCCPC and comfort questionnaires and rough notes. I was systematic about implementing the decisions I made with regard to the sampling strategy, the methods and eventually the analysis. In this manner making any difficulties which became a threat transparent. In chapter six, I was explicit about threats to the validity of each stand alone method, but also demonstrated how each, with its own epistemological underpinnings could become woven into my conceptual framework to aid exploration of contextual comfort and discomfort. In combining methods, I had systematically extended perspectives to aid this exploration, and therefore my possible dominance within these processes warranted the above address.

Triangulation was the main strategy I used to achieve validation, chapter 7 explains how I interpreted and triangulated the raw data, which helped counter threats to validity, such as significant other or researcher biases, and missing data. I then reflected upon the developing issues and explained how the data blended to form subcategories. Mason (2002, p.191) argues that 'a single researcher cannot unequivocally claim epistemological privilege simply because they belong to a specially defined social group or occupy a specific social location' but that if such strategies are used effectively

...it should enable you to show both that you have understood and engaged with your own position, or standpoint, or analytical lens , in a reflexive sense, and also you have tried your best to read your data from alternative interpretive perspectives.

The issue of quality will be subject to further scrutiny with the presentation of the findings. Qualitative research methodology shaped the analytical processes and whilst illustration with textual extracts aids methodological rigour, it is a wordy process, which inevitably causes difficulty with word limits. However, the inclusion of direct quotations, and case displays encouraged me to stay true to the accuracy of the data gathered.

## **Conclusion**

This chapter has critically reviewed the process of the research. It reconfirms the complexity of the area of study and places the overall conclusions in context. With the rise of appealing methodologies in learning difficulty research, giving 'voice' to the children and young people has been of epistemological and methodological concern. Therefore, analysis of the role of self has been a major issue throughout this chapter. Theoretical underpinnings aside, in respect of implementing methods there was no simplicity and I soon discovered the very fine line between ethical research and doing the research according to quality standards. The use of case study research involving multiple qualitative methods to gather data to aid understanding of equipment comfort was a good decision, although the individualism of each case contributed to diversity within the subcategories.

## CHAPTER 12

### CONCLUSION

#### Introduction

Children and young people with neurodevelopmental disabilities are one of the main client groups using adaptive positioning equipment. Comfort is of major importance as some users may spend several hours positioned in an item of equipment. The starting point for this study was fear of discomfort going unnoticed in a specific group of users, children and young people with severe physical, learning and communication difficulties. This user group is unable to use speech and language to communicate about their discomfort whilst being reliant on others to meet their need for positional change to alleviate it. Discomfort is the subjective experience of an intrusive bodily pain sensation. The overall purpose of this study was to gain an enhanced understanding of equipment comfort and discomfort in this user group. The choice of case study reflected a commitment to keep a focus on the individual owning the experience, whilst allowing for the inclusion of significant others linked to the child or young person. Thirteen cases were used in the main study; narratives and observation, parts of which are presented throughout the thesis as exemplars, provide the essential grounding for the interpretations and conclusions drawn from the study. The findings offer new knowledge about the usability of adaptive equipment in terms of comfort and discomfort. The first part of this chapter reviews the findings of the research. The second part presents a framework for the integration of the findings into a set of propositions that can be used to explain, guide and further legitimatise understandings of comfort and discomfort when using adaptive equipment. In the third part I return to the original rationale to raise key issues relating to the project's overall successes and challenges before finally offering future directions for practice and research.

#### **Understanding adaptive equipment comfort and discomfort: behavioural expressions, situational clues, attentive caregivers**

The behavioural expressions provided the starting point for trying to understand the nature of comfort and discomfort in children and young people who do not use language or speech to communicate. Not previously linked through the process of research to everyday adaptive equipment use, I was able to report on those expressions which had an impact on others. Those who had a close relationship with the child or young person affirmed the categorical nature of the emotions and

behavioural expressions. It was the negativity of the behavioural response, in comparison to a more contented state, which they perceived signalled the existence of discomfort. Although this was clearly articulated there are issues relating to possible oversimplification. The behaviours identified by significant others were not exclusive to or solely attributed to equipment discomfort. They did however signal a situation, a bodily experience or an event causing distress. Acute pain and attention/comfort seeking behaviours were mentioned. Whether or not it was the adaptive equipment causing the child or young person distress in some instances remained unclear, particularly for those whose communication was pre-intentional. Nonetheless, distress potentially caused by a discomfort prompted significant others to take responsive action.

The significant others were also able to recognise happiness, suggesting the experience of more pleasant sensations, and again facial expression was a key clue. Moreover, these occurred when the child or young person was occupied in the environment. Contentment with no overt expressivity was another finding. However, interpretation of this expression within the context of comfort and discomfort only became possible when examined alongside the situational clues as interrelating parts of a whole.

A wheelchair, an adapted seat, a standing frame or sleep system are technologically and scientifically designed items for physical positioning. They locate and hold the human body in specific positions, and straps are invariably necessary for safety. Alongside errors of positioning, with hastiness of care tasks at certain points in the day often the cause, the restrictive nature of equipment accessories and the procedural stretching of tissues prior to application raised questions about discomfort; for example, leg splints applied prior to standing frame use. The children and young people do not have the capacity to understand the reasoning which underpins this source of discomfort, only the attention or distress it brings. The intermittent nature of the negative expressions during such a procedure may indicate that the children and young people can rise above the initial stretching discomfort and begin to accept the imposed position if attentive care giving and distraction is provided. The equipment must be used with purpose and functionality in mind. Professionals rarely experience the child or young person's arrival home when end-of-day fatigue is a major factor. Equipment may have fulfilled its purpose of enabling performance and participation during the day, but it cannot be assumed that the same items permit rest and relaxation.

A theme integral to furthering an understanding of comfort and discomfort was the nature of the interpersonal relationship between the significant others and the children and young people. The significant others were all directly or indirectly accountable for the transfer of the child or young person into and out of the equipment, and for the manner and duration of equipment use. Individual contexts, each with their organisational routines, influenced equipment use on a daily basis. Parents experienced adaptive equipment in the context of family life. Teachers, therapists and support workers used equipment in the context of their professional activity, often in busy educational environments. When a son, daughter, pupil or student displayed negative expressive behaviour this information required processing. Sometimes the decisions made were unilateral, at other times shared, but they were not based on isolated decisions taken by people unfamiliar with the child or young person. In their attempts to comprehend the needs of the children and young people, the significant others interpreted pre-intentional and pre-linguistic forms of communication. Caring for and about the children and young people, the significant others adopted a fundamental person-centred ethic which underpinned the delivery of these everyday practices. This was shared by family and classroom staff and therapists alike. The therapists, for example, were not unaware of the distress some items of equipment used to address therapy goals could evoke. Working alongside classroom staff they regularly removed the child or young person from the equipment in cases of uncertainty.

### **Comfort and discomfort: a concluding synthesis**

The dependency of the children and young people in this study meant they did not use equipment in isolation from significant caregivers who possessed the capability to make environmental opportunities possible. Although there are high expectations that all types of adaptive equipment are both aesthetically pleasing and comfortable, the findings of this study substantiate the possibility that discomfort can occur and is an early feature in some cases. Yet in the presence of attentive caregivers a state of contentment, adaptive functioning and participatory use became possible. The different factors underlying comfort and discomfort were discussed in chapter 10, and from these contextual findings I am able to conclude that the same item of equipment can be both comfortable and uncomfortable. However, as part of the social and interactional world in which the children and young people live and learn, and given the complex nature of their physical, learning and communication difficulties, it is others who must accept responsibility for seeing that comfort is

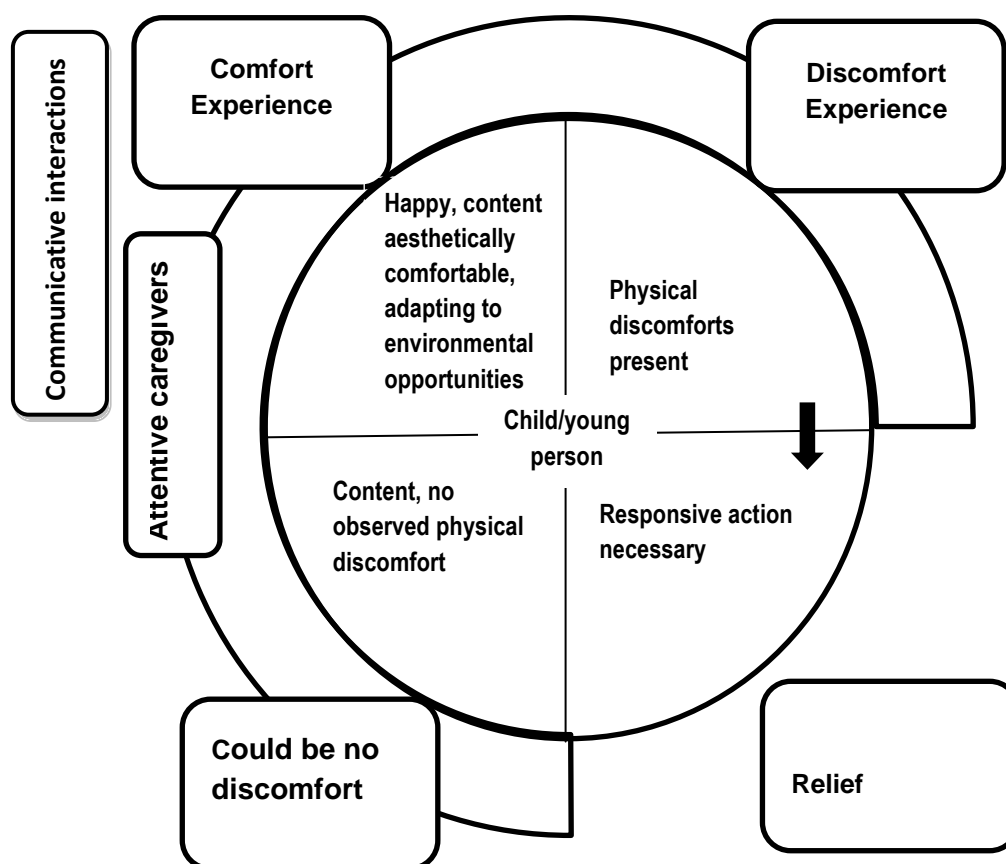


maximised and discomfort minimised at all times. A number of deliberations contribute to this conclusion, which I present diagrammatically in figure 12.1.

- The child or young person experiences physical discomfort from the equipment, and the rate of onset of this experience varies from individual to individual.
- Behavioural expressions, largely facial and vocal, interpreted by those with whom they have an interpersonal relationship would indicate the child or young person is unhappy or distressed. Responsive action is taken. If equipment discomfort is the source, the child or young person then experiences a sense of relief upon removal from the equipment.
- The child or young person appears content, and the significant others are not aware of physical discomfort disturbances, or there is no discomfort.
- The child or young person using the equipment is observed by the significant others to be content or happier than expected, with environmental/interpersonal opportunities appropriately facilitated, and appears comfortable.

The word comfort in the context of equipment use is often considered a universally understood term. This also applies to the adaptive equipment of bespoke design, with manufacturers, designers and professionals often describing an item in terms of its comfort. Comfort and discomfort, like pain, are subjective phenomena, and in the context of equipment use the experiences belong to the user. However in the context of this study the experience also depends on caregivers because the children and young people cannot be positioned in or removed from the equipment without assistance. Nor can they seek out environmental opportunities which may be pleasurable and comforting without assistance.

Figure 12.1 A model of adaptive equipment comfort and discomfort, the child and significant others



As the findings suggest, there are features of equipment design which may contribute to the experience of use being one of comfort but, used excessively or inappropriately, well designed equipment will produce experiences of an adverse physical nature. Whilst the children and young people in the study often appeared contented, and notably free from discomfort, the rate of onset of discomfort varied, which is not surprising in view of the varying health conditions of the children and young people. Avoidance of the factors causing discomfort of necessity therefore became the responsibility of the parents, teachers, teaching assistants and therapists, who were alert and responsive to behavioural change and the point when they believed relief from the equipment was necessary. In this study the children and young people were given opportunity to experience this relief. These findings would indicate that achievement of a comfort experience is also a holistic caring process that requires caregivers to be attentive and have an empathetic awareness of what the child or young person may be experiencing. Caregivers required an understanding of their role in helping eliminate potential physical causes of discomfort, both in terms of initial positioning within the equipment and of on-

going vigilance whilst the child or young person is using equipment. This also includes attention to the mode of engagement, task or activity being undertaken by the child or young person whilst using the equipment. If unhappy behavioural expressions continue after removal of a presupposed discomfort source the likelihood is that discomfort is due to another source of distress.

If equipment is customised to requirements, as the word adaptive suggests, the child or young person is positioned without errors, and an agreed, individual care plan with time restrictions on equipment use is in place, potentially intrusive bodily sensations of discomfort should be minimal. Contented behavioural expressions could suggest there is no discomfort present, but is the child or young person comfortable? Children and young people are not positioned to enjoy equipment per se. Enabling adaptive functioning, participation and enhanced communicative opportunities within the environment are key aims of adaptive equipment use. If such opportunities are missing children and young people may not appear content, or exhibit expressions of happiness, even in the absence of factors known to cause discomfort. It is people who make these environmental opportunities possible. Findings from the current study suggest the quality of environmental and interactional opportunities influences how well children or young people tolerate or like adaptive equipment. In the absence of observed physical discomfort factors, the re-appearance of unhappy behavioural expressions may therefore be due to limiting factors in the environment. Again the vigilance of significant others is required to monitor the child or young person, the equipment and the situational context.

A distinction can be made between postural management, which customarily involves adaptive equipment, and postural repositioning, which includes a change of position. Postural repositioning could be scheduled or unscheduled. A seated position is not the position of choice for many special school curriculum activities. Careful curriculum or care planning indirectly dictates that the child or young person's position be changed. In addition personal hygiene activities require positioning changes. Both bring relief, one type of comfort, as a positional change from the seated position becomes necessary.

There was another explanation for choice about the use of adaptive equipment, not always related to observed discomfort or need for relief. Parents want their child to have some freedom in the home, a place of relaxation, of 'letting go' at the end of a long school day. This was achieved by freeing the child of those positioning straps and splints. They spoke of their son or daughter's relief with that freedom. They

have witnessed the tiredness at the end of a long school day, with some children and young people spending up to an hour in transit. The families accepted the role of adaptive equipment in the work undertaken within the school context, but the parenting element of care, comfort and protection from discomforting experiences was strong. Home is home, school is school.

With the inclusion of both children and young people in this research, a combination of current and retrospective experience was reflected upon in the interviews. Families recounted early experiences of equipment use, both positive and negative. The younger children in the study have the advantage of aesthetically more pleasing, and supposedly more child-friendly, equipment in comparison to those young people in the study at an equivalent age. This however is no indication of earlier acceptance, by either the child or family. One unpleasant experience or technical hitch that results in a distressed child which is perceived to be related to equipment may have long term consequences. The family may be selective, reduce or abandon the use of certain items of equipment in the home.

A number of the children and young people in this study suffered pain as a consequence of secondary musculoskeletal health conditions, for example pain from a dislocated hip. Extra pain and distress may be caused if equipment also causes physical discomfort. These children and young people with physical, learning and communication difficulties do not have the capacity to understand the clinical reasoning which underpins equipment use. They may however be aware of the authentic presence of a caregiver who cares about their wellbeing, and this may in some way help alleviate some of the distress. The 'voices' of the children and young people can be heard if situations are shared and if professionals feel able to put aside their own agendas to address the comfort requirements of the children and young people.

### **The successes and challenges of the research**

A developmental health condition denies the children and young people in this study a universal means of human mobility, the act of walking. In consequence, they spend a good proportion of their waking day not just in a sitting position but supported and secured in this position. They cannot sit in a conventional classroom or dining chair, because of the high risk of falls. Highly engineered adapted seating systems using postural management approaches were developed to address this need, closely followed by consideration of other postural positions such as standing

and lying. One of my aspirations at the beginning of this study was to give 'voice' to the users of this equipment, but especially to those who were unable to use verbal language. I wanted to focus on comfort and discomfort; my rationale being that for people without mobility difficulties, prolonged sitting and restriction of movement is known to cause discomfort.

This research highlighted that significant others interpreted the appearance of key behavioural expressions as representing a distressing event for the child or young person. They took antecedent events into consideration before relating the distressing event to equipment discomfort. Nonetheless, their response, the problem solving involved and any subsequent action which may, or may not, relate to equipment discomfort, demonstrated a caring, humanitarian regard for the child or young person. This applied to all members of the team including the therapists. The expressive behaviours signalling pain, discomfort or another source of distress prompted the problem solving. This appeared to promote the development of experiential knowledge. Successful interpretation of discomfort sources by the significant others reaffirmed their knowledge of the antecedent factors in this group of children and young people. In this study the 'voices' of the children and young people are heard, and lead to everyday methods of practical action.

On another level, if comfort and discomfort-like pain are irreducibly subjective experiences and belong to the child or young person, where does this leave the observations of the significant others? They may express the nature of such experiences using language, for example, if these individuals adopt a postural position for too long, sit in a confined space or wear restrictive clothing. The significant others used the words comfort and discomfort freely. The parents of two of the participants had actually sat in the adapted seats to experience its comfort. Ludwig Wittgenstein, an influential philosopher of the 20<sup>th</sup> century, contended that some words obtain their meaning from their correspondence to objects of reality (Slife and Williams, 1995). Wittgenstein fittingly gave the example of a chair, whilst arguing that less concrete terms do not come into this category. Words such as pain, comfort and discomfort, do not have the same spatial location as a chair. To give meaning to these more abstract words requires social agreement, as Van Hooft (2006, p. 189) states:

I cannot have learnt what the word 'happy' means just by noting my own internal states. How do I know that the state I am experiencing is the state that our language designates as 'happiness'? By seeing that my

expressions of that state are similar to the expressions that others evince when they are standardly described as happy.

Wittgenstein aptly used another pertinent example, the word 'moaning'; a word used to describe an expression which has also acquired meaning over time. I previously described the non-verbal behaviours of the children and young people. These were communicated to me using familial language statements by the participants who had a close relationship with the child or young person. This was possible because they had previously ascribed meaning to these words or statements. Discomfort due to physical processes is sensory, meaning it is a bodily experience felt in the body, rather than in thought (van Hooft, 2006). If a caregiver has previously experienced a bodily discomfort then the words they use to describe that experience to others will have personal meaning. If this caregiver subsequently interprets a child's behavioural expression and gives recognition to a known distressing stimulus, there is some possibility that the behavioural expression is in response to a real experience.

In the context of the research questions, I aimed to develop a research methodology that would place children and young people who do not communicate using language as central participants, not objects of study. As I struggled to make sense of the data, on more than one occasion my thoughts drifted toward mainstream physiotherapy and those more familiar research designs, where a complex and tangled set of findings appears less often on the agenda. Nonetheless, by embracing personal and professional perspectives, the resultant methodology reflected where I had arrived in my professional career. The pre-designed case study gave structure to a research design known for its flexibility; I realistically engaged in the process which allowed real-world data to be generated. As a health professional, I had crossed boundaries to undertake fieldwork in an educational setting. Whilst the ethics of such a design proved to be complex, the completion of the research project is testimony to what is possible. With ethical sensitivity, I situated the study where these children and young people live and learn; environments full of influences. In reality, I could only illustrate the irreducible subjective experiences of the children and young people by making the contextualised experiences of the parents, teachers, therapists, teaching assistants, key workers and myself explicit. I have tried to balance these views and let the data itself tell the story. However, by integrating these interpretations with key empirical and theoretical works the contextual findings become more dependable.

## **Implications for practice**

This group of children and young people with severe and profound physical and learning difficulties may still receive their education in a special school.

Nonetheless, inclusion does exist. To get from the classroom to the dining room, to whole school assembly, to the playground or to the local shops requires safe mobility. Attention to individual postural support requirements maximises safety, whilst enabling the child or young person to be included and have access to a variety of social experiences. This therefore remains an important interventional outcome for this specific group of individuals.

Although children and young people with profound and severe learning difficulties have differing states of alertness, enhancement of adaptive functioning is a mutual, interdisciplinary, interventional outcome for all professionals working in special education schools. Some barriers may exist but interdisciplinary working can flourish in such environments, with the different professional groups utilizing assistive equipment and technology to address specific goals. Teachers, teaching assistants and key workers may perceive themselves as having a lesser role in the primary decision-making with regard to adaptive equipment use, a role accepted by the allied health disciplines. Yet their influential role in curriculum planning, care planning and delivery must be acknowledged, and importance accorded to on-going fostering of collaborative working practices. The teacher designs a core learning programme suitable for all pupils in the class but, of necessity in the current contextual settings, has to take into account the specific health care needs of the individual learner. The teaching assistant or key worker, as an important member of the team, has a broad role that includes daily caregiving. Postural management equipment helps professionals achieve both health and educationally related goals with the children and young people. This, therefore, gives the professionals shared responsibility for planning a balanced programme which gives consideration to both postural management and postural repositioning to aid comfort.

For the child or young person in receipt of adaptive equipment, their family, and those who educate and support the individual during the day, its use should not be seen as a burdensome, unpleasant barrier to daily routines, otherwise the equipment will not be used. Like parents, an empathetic caregiver may experience distress on seeing the child or young person in pain or discomfort and be reluctant to cause further distress. After all, many of these children and young people already experience chronic pain as a consequence of secondary musculoskeletal health

conditions. Certain items of equipment have more restricted use, for example, the standing frame, and for some individuals this item appears to promote early onset of discomfort. However, if a collaborative team pre-plan situational, interactional and curriculum distractions, such equipment can address both the postural management and postural repositioning needs for some individuals. .

Parents are generally supportive of postural management practices at school but often struggle with the restrictive nature of some items. Where both postural management straps and safety straps are utilized, attentiveness, accuracy in application and accurate communication of purpose to all who have positioning responsibility is a universal recommendation. Finally, parents desire relaxation for their children with time out of restrictive equipment and professionals working with them to achieve this would be in keeping with family centred models of practice.

### **Implications for future research**

To enhance understanding of the findings, I perceived a need to search for meaning in readings largely outwith my own propositional knowledge, branching into subject disciplines outside health. Adaptive equipment, particularly seating, provides a microenvironment in which the child or young person may be comfortable or uncomfortable. This may influence states of alertness, communicative interactions and other aspects of functioning. With enhanced knowledge of expressive behaviours afforded by research teams, Breau *et al.* (2007) found that children with profound developmental disabilities who experience pain perform fewer adaptive skills. Therefore, there appears to be scope for replication of earlier studies that have evaluated different items and types of postural management equipment. Additional research team members would be a recommendation, inclusive of a speech and language therapist, an educationalist and a behavioural psychologist. The current study was of exploratory design, and a series of case studies using mixed methods, including quantitative and ethnographic method, would be the next step using more defined inclusion criteria.

Discomfort is not unique to those who do not use language and in the preparatory stage some clients using positioning equipment were interviewed. Most of the literature on wheelchair-seated comfort involves adults. There is scope to extend understanding of children's lived experiences by talking and listening to children and young people who use adaptive equipment and who can express their views and experiences through speech or an augmentative communication aid



Across many spheres of practice therapists as a group of allied health professionals favour outcomes which can be defined plainly. This applies to pain and discomfort. Pain assessment is perceived to be useful in the evaluation of treatment outcomes. However pain research studies often utilize measures of pain or discomfort that designate a neutral sense of comfort; this being the absence of a specific discomfort (Miaskowski *et al.*, 2006; Kim and Kwon, 2007), thus making assumptions about comfort. In the current study comfort was often implicit if the individual was content and receptive, and the equipment visually appeared comfortable. Discomfort identification was the challenge as distress warranted more immediate action. Staff resources in special education would exclude the use of a time-consuming checklist. However, an adapted version of the comfort taxonomy (Kolcaba, 2003), alongside a shortened list of common behavioural pain indicators (Hadden and Von Baeyer, 2005) might maintain focus on both comfort and discomfort. Finally, this research gives encouragement to interdisciplinary researchers who pursue evaluation of affective behaviour using experimental case study designs. With some experiential knowledge, I often came to the same conclusion and followed similar lines of reasoning as the significant others when interpreting the expressive behaviours of the children and young people. Nonetheless, consciously aware of my deficit in extended tacit knowledge for this particular group of individuals, there is scope for practitioner researchers in special education to generate and analyse mixed methods data whilst pupils using equipment engage in curricula activities.

### **Final summary**

This study aimed to enhance understanding of how children and young people with severe physical, learning and communication difficulties have their comfort needs met when using postural management equipment. Threats to comfort from adaptive equipment use include the restrictive nature of various accessories, hastiness of care tasks producing positioning errors and the procedural stretching of tissues prior to application. A state was discernible where the children and young people appeared at ease, possibly without discomfort, within the microenvironment which adaptive equipment provides whilst allowing access to peers, the learning environment, social interactions, school assembly and play areas.

Opportunities for lessening discomfort sensations exist, including the pre-planning of daily routines and environmental opportunities, alongside time out of the equipment for relaxation. However, as the same item of equipment can be both comfortable and uncomfortable for children and young people dependent on others

to gauge their need for positional change, adaptive equipment use must be intrinsically coupled with attentive care giving. Enhancing equipment comfort for children and young people with physical, learning and communication difficulties means that, even when time pressures exist, professionals and caregivers in health and education need to create opportunities for interpersonal interactions that allow the behaviours which express pain or discomfort and pleasure to be identified. Responsive action can then be taken if necessary.

The study reinforces the utility of adapted and individualised equipment, especially adapted seating with its potential to provide greater opportunity for participation in life situations and concurrent access to contemporary educational strategies and social skills training. If therapeutic positioning using adaptive equipment is to be centred around the individual needs of the child or young person, and given the complex nature of their physical, learning and communication difficulties, it is others who must accept responsibility for ensuring their optimal level of comfort.

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## APPENDIX 1

Summary of the Gross Motor Function Classification System (GMFCS) Full details available <http://www.canchild.ca/en/measures/gmfcs.asp>

This tool uses an ordinal scale (Levels 1-V) to classify the gross motor function of children and young people with cerebral palsy with particular emphasis on sitting, walking, and wheeled mobility. It gives emphasis to children's function rather than their limitations. Descriptors for each level include: gross motor function, the need for assistive technology, including hand-held mobility devices (walkers, crutches, or canes) or wheeled mobility. Separate descriptions are provided according to age. It was developed in 1997, with a 2007 expanded and revised version (GMFCS - E&R), which includes an age band for youth 12 to 18 years. The table below provides a short summary.

	2-4 years	6-12 years	12-18 years
1	Children get into and out of, and sit in, a chair. They walk indoors and outdoors, and climb stairs. Emerging ability to run and jump.	Walk at home, school and outdoors. Climb stairs without rail. Speed, balance and co-ordination of gross motor skills are limited.	Young people Walk at home, school and outdoors. Climb stairs without rail. Speed, balance and co-ordination of gross motor skills are limited.
11	Children sit in a chair with both hands free to manipulate objects. They can walk without the need for any assistive mobility device indoors and for short distances on level surfaces outdoors. Children climb stairs using a rail but are unable to run or jump.	Walk in most settings, use rail to climb stairs. May use an assistive device to walk long distances. Running and jumping difficult.	Young people walk in most settings but this is influenced by environmental and personal choice. May use a hand held mobility device for safety and wheeled mobility for long distances outdoors. Use a rail to climb stairs.
111	Children require pelvic or trunk support to maximize hand function when using a regular chair. They walk with an assistive mobility device on level surfaces and climb stairs with assistance from an adult. They are transported when travelling for long distances or outdoors on uneven terrain.	Uses a hand held mobility device to walk indoors. Uses a wheelchair for long distances and may self propel for shorter distances.	Young people are capable of walking using a hand held mobility device and may climb stairs holding onto a rail. May self propel a manual wheelchair or use a powered wheelchair at school.
1V	Children use adaptive seating for trunk control and to maximize hand function. They may walk short distances with a walker and adult supervision but have difficulty turning and maintaining balance on uneven surfaces. Children may achieve self-mobility using a power wheelchair.	Use methods of mobility that require physical assistance or powered mobility in most settings. They may walk short distances with physical assistance, use wheeled mobility or a body support walker when positioned. They are transported in a manual wheelchair outdoors or use powered mobility.	The young person uses wheeled mobility in most settings. Physical assistance of 1 to 2 required for transfers. They may operate a powered wheelchair, otherwise are transported in a manual chair.
V	Restricted voluntary control of movement and ability to maintain antigravity head and trunk postures. Functional limitations in sitting and standing are not fully compensated for through the use of adaptive equipment and assistive technology. The children have no means of independent mobility and are transported. Some children achieve self-mobility using a power wheelchair with extensive adaptations.	In all setting transported in a manual wheelchair. Limited in their ability to maintain antigravity head and trunk postures and control leg and arm movements.	The young person is transported in a manual wheelchair in all settings. Limited in their ability to maintain antigravity head and trunk postures and control leg and arm movement. Self-mobility is severely limited even with the use of assistive technology.

### **Distinctions between Levels I and II**

Compared with children in Level I, children in Level II have limitations in the ease of performing movement transitions; walking outdoors; the need for assistive mobility devices when beginning to walk; quality of movement; and the ability to perform gross motor skills such as running and jumping.

### **Distinctions between Levels II and III**

Differences are seen in the degree of achievement of functional mobility. Children in Level III need assistive mobility devices and frequently orthoses to walk, while children in Level II do not require assistive mobility devices after age 4.

### **Distinctions between Level III and IV**

Differences in sitting ability and mobility exist. Children in Level III sit independently, have independent floor mobility, and walk with assistive mobility devices. Children in Level IV function in sitting (usually supported) but independent mobility is very limited. Children in Level IV are more likely to be transported or use power mobility.

### **Distinctions between Levels IV and V**

Children in Level V lack independence even in basic antigravity postural control. Self-mobility is achieved only if the child can learn how to control a powered wheelchair.

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## APPENDIX 2

The tables included in this appendix provide an overview of the adaptive seating and postural management literature. This literature synthesis was extracted from the following databases: CINAHL, PubMed, ERIC, Medline, Cochrane, ProQuest Nursing and Allied Health Source, ASSIA, Zetoc, Applied Social Sciences Index and Abstracts, Science Direct Freedom Collection and Web of Knowledge, accessed using search engine NORA. UK paediatric therapy journals were also hand searched for relevant articles.

The parameters of the search were broad, not exclusive to CP, but children or young people with neurodevelopment disabilities, including CP, multiple disabilities or PMLD up to 22 years of age using the following additional key words: adapted seating, special seating, specialized seating postural management, 24-hour postural management, night time positioning, postural care, postural support, standing devices, sitting, standing or lying orthoses. The search revealed quasi-experimental group designs, single subject design, descriptive accounts, case studies, surveys and systematic reviews with outcomes used to evaluate effectiveness varying over time. I have divided the literature into the following three sections:

- Publication of systematic / literature reviews on the topic
- Studies with a postural management intervention published since 2007, and not included in the above reviews
- Studies published since 2000 examining contextual influences



## APPENDIX 2

### Adaptive Equipment Literature Synthesis

#### Published Systematic/ Literature Reviews (reviews search literature from 1980-2007)

Author and Purpose, Type of Postural Management	Search Strategy	Rigour	Findings	Conclusion
Ryan <i>et al.</i> (2011) Systematic reviews of adaptive seating	1990 -2010 Data base Abstract search of reviews of effects Cochrane database of systematic Reviews Ovid Medline Ovid Health Star PsycINFO	Used expanded and revised version of GMFCS to classify children with CP  Overview Quality Assessment Questionnaire Applied	Initial pool of 195 articles. Critically appraised	Future studies should specify the developmental and functional level of participants. Adoption of core group of evaluative measures Adequate levels of reliability and validity and be responsive to meaningful changes in dimensions of the expanded ICF CY  Recommends future prospective, cohort analytic designs, single subject methodologies and qualitative inquiry
Wynn and Wickham 2009.To evaluate the evidence for the efficacy of night time positioning equipment (NTP) for children with postural needs. Evidence to guide therapists in their assessment of a child's night-time positioning needs	1997-2007  Medline Embase Cinahl Kings Fund Key word: child, deformity, postural management , positioning , CP, 24 hour positioning sleep system, spine, lying	Inclusion criteria applied  McMaster Critical review form used to evaluate 6 journals  1 study general review of PM	Supporting children with CP in a symmetrical position at night for at least a year slows down the rate of progression of hip dislocation during that time period in some children	Only 3 studies for effectiveness reviewed Efficacy focused on posture Small evidence base, which suggests NTPE reduces rates of hip subluxation, improves care and reduces pain.  NTP part of postural management

**Published Systematic / Literature Reviews (reviews search literature from 1980-2007) (continued)**

Chung <i>et al.</i> (2008) The effect of adaptive seating on sitting posture/ postural control in children with cerebral palsy(birth to 20 years) Do changes in postural control relate to other aspects of functioning?.	1980-July 2007 Medline Embase, Cinahl, DARE,PEDRro Cochrane Database of Systematic reviews Web of science Dissertation abstracts ERIC PubMed	14 articles Screened for inclusion criteria Indexed outcomes to ICF Assigned levels of evidence Assessed study quality	Significant improvements for seat inserts, external supports and modular seating systems. Weak evidence for effects of postural control on functional abilities. Conflicting reports for seat /back angle and saddle seats.	Only studies in English  All CP, but mild, moderate and severe.  Future studies must include outcomes other than postural control.
Farley <i>et al.</i> (2003)  To determine the evidence base for postural management.	Medline, Cochrane Reviews Cinahl Posture /postural management: physiological function. Neonates, children under 5.CP Neuromuscular, scoliosis Neurological conditions Older People, Activities of daily living	Assigned Sackett's levels of evidence 150 articles very broad inclusion criteria (neonates- older people)	Positive outcomes of a range of postural management strategies, but stronger level evidence for cardiorespiratory physiological level outcomes than for functional outcomes.	Very broad inclusion criteria  Review range
Keeth <i>et al</i> (2008) How effective is adaptive seating for children with orthopaedic or central nervous system involvement in increasing attention or participation in class?	Electronic databases Cinahl, Pubmed Eric Medline Cochrane AOTA website Key words adaptive Under 21 seating, function, CP, positioning, seating, orthopaedic, upper extremity function, neuromuscular impairments, neuromuscular disorder, neurological , therapeutic positioning, classroom, tilt , attention, participation	Exclusion criteria applied. Assigned levels of evidence	No direct evidence to support or refute the outcome of increasing attention or participation in class, although studies of effectiveness on upper limb function may indirectly relate to attention and participation. Angle of seat /incline varied between studies Adaptive seating effective in improving posture and enhancing pulmonary function. Neutral to forward inclined seats can affect child function.	Adaptive seating appears to enhance function , but inconsistent findings  Practice should be individualised , and individual outcomes measured.

**Published Systematic / Literature Reviews (reviews search literature from 1980-2007) (continued)**

McNamara <i>and Casey</i> (2007) Seat inclination on postural control, muscular activity and upper extremity function in children with CP, all types.	1990 -2006 Cinahl MEDLINE AMED Embase Cochrane Library of Systematic review Web of Science OTD Base 13 DATA BASES Posture management, posture, positioning seating, static seating seat angles , seat inclinations, children, young people, paediatric, pediatric , upper limb function, upper extremity function, CP.	Inclusion criteria applied to abstracts 10 articles (4 single case design, 2 longitudinal, 4 between group design) reviewed and critical appraised using McMaster guidelines.	Studies for postural control produced conflicting evidence: 3 advocated posterior tilt, with positive outcomes 2 studies advocated an anterior seat base 3 studies forward tilt seat combined with positioning of pelvis upper body and feet Studies for upper limb function produced conflicting evidence, but anterior tilt seats significantly increase arm and hand function Reclined position increased muscle tone.	Specific outcome reviewed for one health condition, but all types of CP.  Anterior and neutral inclines positively affect function increase arm and hand function.  Inconsistent findings  Children with CP need to be assessed individually.
Michael, Porter & Pountney (2007) To determine the effects of tilt-in-space seating on outcomes for people with neurological or neuromuscular impairment who cannot walk.	Electronic databases Cinahl Embase Amed Medline	15 articles 10 studies include children, 9 studies include adults Interventional studies using tilt or observational studies for existing users of tilt Evidence classification of evidence.	Evidence ranging from level 11-level 1V	All non-ambulant participants, broad range of health conditions Broad range of interventions /outcome measures/heterogeneity of included samples Posterior seat position reduces pressure under ischial tuberosities Limited evidence on tilted seat position of function and participation.

**Published Systematic/ Literature Reviews (reviews search literature from 1980-2007) (continued)**

<p>Stavness (2006)</p> <p>To determine the most appropriate sitting position for children with CP to promote energy conservation and optimal functional abilities.</p>	<p>1980- 2005</p> <p>Cinahl, AMED, Healthstar, PubMed</p> <p>MEDLINE, EMBASE, Cochrane Central Register of Controlled Trials OT Therapy Positioning Wheelchair, Postural Control Adaptive seating devices Patient Positioning Cerebral Palsy Movement Disorders, Upper extremity , reaching , grasping Occupational seeker and Pedro</p>	<p>Screened for inclusion criteria</p> <p>16 articles reviewed to determine how alignment of pelvis affected upper extremity function.</p>	<p>Majority of evidence positive effects of neutral to slightly forward orientation , a hip belt , an abduction orthoses ,footrests and cut-out tray.</p>	<p>Studies included lacked methodological rigour</p> <p>No Assigned levels of evidence</p> <p>Assessed study quality sub classification of CP</p> <p>Exact seat angle and orientation in space should be determined on an individual basis.</p>
<p>Harris et al.(2005)</p> <p>To determine the effectiveness and efficacy of postural control interventions</p>	<p>1990-2005</p> <p>CP GMFCS 1-V</p> <p>Birth to 19 years</p>	<p>12 studies 5 included seating devices</p> <p>10 group designs and two single subject designs Screened using Sacket's levels evidence studies ranging 11-1V.</p>	<p>Level of evidence ranged for 11 to V, with 4 level 11 evidence , 1 level 3 evidence, 6 level 4, 1 level 5 67% moderate to high level score</p> <p>Highest level of evidence obtained for two studies comparing adaptive seating interventions (Washington et al, 2002; Reid, 1992). Two include level 1v and 1 level V.</p>	<p>Specific outcome reviewed for one health condition, but all types of CP</p> <p>Broad intervention inclusion criteria.</p> <p>Diverse measures of postural control</p> <p>Difficulties combining heterogeneous studies.</p> <p>Of the 2 studies with high level evidence , severity of health condition not reported, and the children in the other study were mild/moderate.</p>
<p>Roxborough(1995)</p> <p>To determine the efficacy and effectiveness of adaptive seating in achieving proposed outcomes , and whether other outcomes have been researched.</p>	<p>Inclusion CP birth to 19 Seating</p> <p>Adaptive seating Positioning</p> <p>1982 -1994</p> <p>Cinahl</p> <p>Psychological Extracts</p> <p>RESNA and AIS conferences</p>	<p>years Adaptive seating</p> <p>Unsupported seating for comparison, those with implication for interpretation of reported outcomes</p> <p>Exclusion criteria Validity assessment Sackett levels of evidence</p>	<p>8 studies met inclusion criteria</p> <p>3 studies generated level 1 evidence supporting effects of pulmonary function, active trunk extension ,and test performance on Bayley mental scale</p> <p>Grade B on effect on reach.</p>	<p>Single reviewer</p> <p>Outcomes of adapted seating not researched in the literature: musculoskeletal deformity, increased comfort, and ease of care.</p>

## Appendix 2

### Intervention: Studies published since 2007

Purpose and method of PM	Study design	Sample	Outcome measure	Findings /conclusions	Strengths and limitations
Costigan and Light (2010) Investigation into the effect of seat position on upper( UE) extremity access to augmentative communication ( AC) for child with CP.	Single subject ABAB design Comparison of child's typical position and intervention position using current clinical /research conventions for promoting UE function.	N=1 Inclusion criteria Age 1-17 5years Diagnosis CP, motor skill limitations affecting accuracy and speed of target selection Uses wheelchair for mobility Uses ACC Success at target selection tasks.	Seating analyses Frequency of accurate selection of ACC device Speed of accurate selection of ACC device Both defined Procedural reliability 97% Accuracy data agreement 95%	Seating analyses reported Frequency of accurate selection Baseline=3.3 Intervention 1=6.4 Intervention 2=6.7 Withdrawal =4 Response time Recorded response times to accurate selection highly variable within phases.	Preliminary empirical evidence for positive effects of functional seating on access to AC, although an adequate level of accuracy for functional communication not achieved Conclusion Functional seating ( FS) –highly individualised and future studied should investigate the principles underlying the conventions of FS, rather than strict implementation of a specific seated position , confirm positive effect across other participants , dependent measures.
Hill et al(2009) To examine sleep quality and respiratory function in Children with severe CP using night-time postural (NTPE) equipment  Method NTPE	Pilot	10 children, mean age 10.9 NTPE user GMFC IV or V	Paediatric Sleep questionnaire Comparison of Pysomnography with and without PME	Group differences, non-parametric statistics for group data. Paired sample T- tests for parametric variables. O <sub>2</sub> saturation higher for three children lower for 6 children using NTPE compared with sleeping unsupported. No difference in sleep qualities, but lower overnight oxyhaemoglobin saturation values, less rapid eye movement sleep and higher arousal.	Children with severe CP risk respiratory complications in sleep irrespective of positioning  Clinical assessment for child using NTPE should include measures of respiratory function.

### Intervention: Studies published since 2007 (continued)

Vekerdy (2007) An investigation into the effects of a special seating device in non ambulant children with CP.	Prospective study, matched pairs ( same subject pre-post intervention Comparison before and after application of a thoracic-lumbar-sacral orthoses with non-rigid SIDO frame (TLSO.SIDO)	N=47 Children with CP Mean age 53.2 months Subgroup of 15 children with significant problems in feeding	X ray of thoracic and lumbar spine Cobb angle measurement GMFC scoring Questionnaire to address daily activities and posture Parental satisfaction 5-point analogue scale Comparison of lateral X-ray view of lumbar spine before and after TLSO-SIDO	27 complete X-rays for analyses No significant difference in pre-post thoracic kyphosis and lumbar lordosis measurements Sub group= decrease in thoracic kyphosis values( $P<0.0001$ ).	Conclusion very difficult to measure the effect of postural management on the development of children with CP Regular application of TLSO.SIDO had a beneficial effect on feeding problems and on posture.
Pountney et al. (2009) Hip subluxation and dislocation in cerebral palsy a prospective study on the effectiveness of postural management programmes. Method PM Programmes.	Prospective Cohort study	39 children with CP commencing use of PM before 18months and historical control	Levels of ability recorded every 3 months Type and usage of equipment recorded Hip X rays, migration percentage 30 and 60th months.	Recommended and moderate levels had significantly less chance of both hips being subluxed than those using equipment at minimal levels (two-tailed Fisher's exact chi (2) $p = 0.024$ ). Children with hip problems at 5 years significantly less in the intervention group (chi (2) = 11.53, df = 2, $p = 0.006$ ). Less need for other interventions- surgery, hip / spinal orthosis, and/or botulinum toxin injections, in the intervention group (two-tailed Fisher's exact $p = 0.001$ ).	PM has an adjunctive role to play in the prevention of hip subluxation in children with CP.
Pountney et al.(2002) The effect of various postural management on controlling hip deformity in cerebral palsy  Method 3 categories of PME.	Retrospective study	59 children with bilateral CP using PM E for < 2 years. Age 1st entry 5 months - 9.8yearsfinal entry 3.2 -18.4	3 categories of PME: 1 =all forms of CAPs systems; 2=2 items of CAPs, =use of CAPS seat only. Hip migration % Record reviewed overtime period s 1.2-16.9 years.	Children using 24 hour PM (ALL CAPS) were significantly more likely to retain hip integrity than children exposed to other systems.	Retrospective approach Prolonged time period +some incomplete accuracy on equipment being controlled for Type of CP, severity and age range and different review period affect hip migration. Children included had been able to comply with PMP.

### Intervention: Studies published since 2007 (continued)

Picciolini et al (2009) Postural management to prevent hip dislocation in CP Plaster casts	Ethical Approval	2 children with CP physiotherapy and seated P M 5 hours per day with siege moule	AP radiographs Reimer migration parentage	Progressive reduction of MP values of the hips treated	Conservative management can influence hip dislocation  Some missing data
Rigby et al (2009) Effect of Adaptive Seating Devices on the Activity Performance of Children With Cerebral Palsy  Adaptive seating one for floor, other for toilet.	Baseline intervention Baseline study	Parents and their children (N=30), mean age of 4 years 6 months, with Gross Motor Function Classification System levels III and IV CP participated.	Changes in activity performance and satisfaction were measured through parent ratings on the Canadian Occupational Performance Measure. We interviewed parents biweekly using the Home Activity Log to describe and explain their child's activity performance during the 3 study phases.	Parents identified 139 activity performance issues (4.6 a child): 58.3% in self-care, 34.5% in play, and 7.2% in socialization and quiet recreation. We used paired t tests to demonstrate significantly improved performance and satisfaction with self-care and play activities when the children used the adaptive seating devices during the 6-week intervention phase. Three themes arose from the analysis of comments made by parents during Home Activity Log interviews: adaptive seating can have an enabling influence on the child, care-givers and family find adaptive seating useful, and the adaptive seating devices did not meet every family's needs.	Parents reported that their young children with CP were more able to engage in self-care and play activities when using specific adaptive seating devices in their home, Parents indicated that their child's activity performance decreased after the seating devices were removed from their homes.

### Intervention: Studies published since 2007 (continued)

Mc Donald and Surtees (2007) Evaluate effectiveness of adaptive seating using sacral pads and knee blocks for a group for children with CP adaptive seating accessories.	Longitudinal study 6 visit trial. Visit 1 &2 intervention. Visit 3 Knee blocks. Removed for 4 weeks. Visit 4 Knee blocks replaced Visit 5 and 6 post intervention.	23 children aged 7-14 with CP 4 limb involvement spastic or dystonic( GMFCS V) PMLD , no verbal communication.	Force through knee block [pressure at sacral pad Postural alignment using goniometer.	No statistically significant correlations be between force ant knee block and changes in postural alignment Force at knee block and pressure at sacral pad Some improvements in hip position.	Children showed variability Groups not homogenous Small sample One researcher collected all data Known measurement errors of goniometry particularly of one researcher.
Mc Donald and Surtees (2007) To measure change in postural alignment when using / not using the active element of one adaptive seating system.	Before and after design Time 1)CAPS11:knee blocks on/knee blocks off ( immediately ) Time 2)Knee blocks off ,after 1 month period knee blocks on  Ethics Written parent , and oral child consent from those able.	23 children aged 7-14 with CP 4 limb involvement spastic or dystonic GMFCS V	Postural alignment taken at each time with knee blocks on and off using the Seated Postural Control Measure / goniometry.	Repeat measures ANOVA No significant difference in angular variations between the conditions Combination of knee block and sacral pad no immediate effect upon joint angle and overall posture immediately after removal or replacement of knee blocks.	Children showed variability Small unrepresentative sample One researcher collected all data Known measurement errors of goniometry particularly of one researcher Need for objective outcome measurement Improved posture is one of a number of factors to consider when deciding upon correct seating Provision should be on an individual basis.



## APPENDIX 2

### Contextual Influences on Equipment Use (Studies) not included in systematic appraisals

Author /date/purpose	Study design	Sample	Results /Findings/	Conclusions Strengths and limitations
<p>Lacoste et al (2009)</p> <p>To review postural stability in the sitting position</p> <p>To identify the parameters related to body geometry, activities of daily living (ADL)</p> <p>To identify period of the day that may link to postural instability.</p>	<p>4 Questionnaires validated by focus group</p> <p>Informed consent from children, parents and therapists.</p>	<p>31 children with CP (8–18 years), their parents and therapists children</p> <p>Use seating within wheelchair</p> <p>Children able to understand simple instructions.</p>	<p>Descriptive analysis</p> <p>81% therapists and 70% parents reported instability</p> <p>In stability occurs after less than half an hour in Sliding and posterior pelvic tilt, pelvic obliquity and pelvic rotation were identified as the main problems of instability</p> <p>perception of the influence of seated postural stability on ADL and seated tolerance was quite different (86 vs. 44% and 58 vs. 28%)</p> <p>Average 11 hours per day usage</p> <p>All subjects could drive their wheelchair, postural instability reported in 20 .</p>	<p>In stability causes difficulty with ADL.</p> <p>Need more objective measure of postural control and seated stability</p> <p>When pelvic instability was attributed to the inadequacy of a seating component, the pelvic belt was blamed in 73% of the cases. Furthermore, its use by various caregivers was reported to be very inconsistent and it was often badly adjusted, difficult to attach adequately or losing its adjustments with time.</p> <p>Research is thus needed to better understand the factors associated with pelvic instability and to find more effective pelvic stabilisers.</p>
<p>Hutton &amp; Coxon 2011</p> <p>To explore teachers and teaching assistant views of how to manage the postural care needs of children with PD in mainstream school.</p>	<p>Qualitative individual and focus group interview.</p>	<p>Purposive sample of 4 primary schools</p> <p>36 teachers and TA's</p> <p>24 hour approach</p> <p>Research questions identified.</p> <p>Data gathering and analytical strategy described.</p>	<p>Teachers and TA's have limited understanding of PM</p> <p>Fe had experience of benefits</p> <p>Followed therapists instructions</p> <p>Emotional aspect of caring for a child with PD</p> <p>Expressed anxiety about causing discomfort</p> <p>Equipment viewed as bulky , uncomfortable and restrictive and not suited.</p>	<p>Restricted to geographic location, although inclusion in mainstream school reflects national policy.</p> <p>Contextual detail provided.</p>

### Contextual Influences on Equipment Use (Studies) not included in systematic appraisals (continued)

McDonald et al (2007) Investigation of the opinions of parents and therapists of children using adaptive seating systems.	Questionnaire 59 families 61% response rate for parents 54% response rate for therapists  Ethical approval	Parents and therapists of children with multiple and complex needs, children did not have verbal communication skills.	Non –parametric statistics for quantitative questions Key word analysis of qualitative questions Responses characterised into domains of ICFs Parents and therapists views differ in key areas Parents: personal and environmental factors explain satisfaction Therapists :body function and structures.	Included question about comfort in individual adaptive seating system Difference in opinion cause for concern. Clinicians must pay attention to the sensitivity of measurements of activity and participation , or domains of ICF Further investigations necessary , concentrating on the activity and participation, environment and personal factors elements of child functioning A focus purely on PM ignores the difficulties experienced by families.
Bush and Biggs (2011) Assisted Standing Experiences of Children with CP and their physiotherapists.	Qualitative study Semi structured interviews	9 children with CP who had used, or currently used standing frames Thematic analysis of interview data.	Children perceived little if any benefit from standing, some found it uncomfortable, others experienced discomfort after standing. Most continued to stand Physiotherapists were convinced that assisted standing was a valuable adjunct to treatment.	Assisted standing was uncomfortable for the children in the study. Views differed as regards psychosocial benefits Both groups perceived the standing frame would produce improvement in body structure and function.
Mayer <i>et al</i> (2010) To identify factors influencing postural management (PM) in special schools  Method PM and varied goals.	Cross sectional descriptive survey 81% rate  Ethics approval	43 therapists 18 teachers working with children with CP in special school setting GMFC 1V or V. Descriptive analysis of demographics Staff roles and benefits of PM. Delivery of Pm programmes.	<b>Barriers</b> 1)Positioning equipment unavailable 2) Difficult to use 3)Lack of time 4) Lack of school staff's knowledge and skills to carry out PM <b>Facilitators</b> 1)Written documentation 2)Communication 3)Timetabling	Diverse variety of responses Clarification of responses not possible Impact on generalizability to other settings.

### Contextual Influences on Equipment Use (Studies) not included in systematic appraisals (continued)

<p>Telfer et al (2010) Investigation into the views of teaching staff members at special needs schools and the parents of children who attended these schools on the provision and current technology of seating systems</p> <p>Adaptive seating</p>	<p>Two similar questionnaires Combination of open and closed questions Institution ethical approval Voluntary</p>	<p>55% staff response (this group-included teacher Occupational therapists, learning assistant and speech therapists 53% parental response Descriptive analysis Mann-Whitney Fleiss's kappa to determine overall rater reliability.</p>	<p>Reported functions by both groups (providing support, providing comfort, positioning for eating and preventing the development of deformities consistently rated by respondents as important. Reported dissatisfaction with reliability of systems and time to obtain replacement systems Time spent transferring per day greater than 1 hour Perceived importance of adaptive seating being accepted by peers statistically significant between the groups.</p>	<p>Reports on adaptive seating as used in practice clinical relevance Need for safety measures /review procedures to cope with wear /tear,/repairs and growth</p> <p>Type of seating not specified Response bias a possibility.</p>
<p>Ryan <i>et al.</i> 2009 Impact of adaptive seating devices on the lives of young children and their families</p> <p>Adaptive seating</p>	<p>Baseline intervention –baseline study.</p>	<p>30 parents and children with CP, age 2-7 years ICF level III or IV Family Impact of Assistive Technology Scale (FIATS) Impact on Family Scale (IFS)</p>	<p>Repeated –measures analysis of variance detected significant mean differences among FIATS scores. Post hoc testing confirmed significant mean differences in scores between baseline and intervention, and intervention and post intervention phases. No within subject change of IFS mean scores Meaningful positive impact on family life Removal of devices had a concomitant negative impact on key aspects of family life.</p>	<p>Restricted to CP  Unrepresentative sample Measurement errors due to design Self enhancing bias Sample not large enough to make inference about the effect of technology as measured by FIATS subscales or judged the parent perceived effect on psychosocial outcomes as measured by the IFS.</p>

**APPENDIX 3**  
**ETHICAL APPROVALS**





















Original fluorescent orange paper, green picture, green and black text

# Good and Bad Things About My Wheelchair



## Want to find out more?



Hi Boys and Girls!

My name is Anne Lyons and I am a teacher of physiotherapy at Northumbria University. As part of my work I am doing a small project about wheelchairs and other equipment your physiotherapist likes you to use. But in order for me to do this I need your help!

I'm sure you have lots to say about your wheelchair, the cushions, the seat belts and other bits and pieces attached to the wheelchair. For my project I want to know what you think and would like you to tell me about the good and not so good things about your wheelchair. I want to find out how comfortable you are in your wheelchair, school chair and standing frame you use during the day. I also want to know how often and for how long you use the equipment.

Now this is where you come in!! I need 5 volunteers to agree to help me. If you decide to help all you have to do is:

- Come down to the physiotherapy room at school at a time I will give you.
- Four of your school friends and your physiotherapist will also be invited. We will talk about your wheelchair and the other equipment you use. You can tell me the good and not so good things about using the equipment.
- Enjoy the biscuits and juice provided
- Then you can go back to your classroom!

Sound ok?? If the answer is yes then all you need to do now is sign this sheet at the bottom of the page and send it to me with your mum and dads! It's important to remember that you can leave at any time if you don't feel comfortable and if you have any other questions make sure you write them down in the box.

Thank you for your time and I look forward to meeting you!

Anne Lyons

➤ I have read the letter sent to me about Anne Lyons project and understand what I will do in the project.

☐

➤ I agree to help Anne with her project.

☐

Name: -----

Date: -----

Other questions?



Date:

Title: Predicting Sitting Discomfort in Children Who Use  
Special Seating and Other Types of Positioning  
Equipment

Parental Agreement for Child to Participate in  
Focus Group

Child's surname /family name.....

Child's first names.....

Date of birth.....

Age.....

Responsible health professional .....

Job title.....

Male

Female

Special requirements.....

# Information Sheet for Parents/Guardians

## Predicting Sitting Discomfort in Children Who Use Special Seating and other Types of Positioning Equipment

---

### WHAT THIS RESEARCH IS ABOUT?

My study aims to investigate comfort and discomfort in children who use special seating and other types of positioning equipment. This is a personal study which I am doing for my doctoral degree at Northumbria University. My director of studies is Dr Anna Jones. I will discuss the study in detail with Dr Jones as it is progressing.

It is hoped the study will inform everyday practice, particularly for health, educational and social care professionals who already work or intend to work with a group of children with disabilities. I understand your child is a wheelchair user, and I would be very interested in

- obtaining his/her views, experiences and opinions of their wheelchair, and his/her perceived levels of comfort and discomfort
- finding out about the length of time your child can comfortably use the prescribed equipment

It is hoped that by giving consent to allow your child to participate in the focus group your child and yourself will be reassured with knowledge that the achievement of comfortable, supportive and functional seating is perceived as a priority for all children with disabilities, including those who cannot communicate.

## WHAT WILL BE ASKED OF YOUR CHILD

If you consent to your child being involved in the focus group I would ask..... to come the physiotherapy room at school together with another four children. The school physiotherapist or a teaching assistant would also be present. The focus group will last about 45 minutes. I will ask the children to talk about their experiences; including the difficulties they have encountered using equipment.

## WHAT WILL HAPPEN WITH THE INFORMATION?

The focus group will be tape-recorded and is confidential. Your child's name or the name of the school will not be used in the report. At the end of the study the interview tape will be retained for two years and then destroyed. The information obtained will be used to develop the next stage of the research.

## SHOULD I ALLOW MY CHILD TO TAKE PART?

It is entirely up to you to decide whether to allow your child to take part in the research. If you decide not to take part, it will not affect the services you or your child receives. If your child decides to participate, he/she can stop taking part, at any time. This will not affect the services you receive in any way.

If you have any questions about the research, please contact Anne Lyons by telephone XXXXXXXXXXXX or by writing to: Anne Lyons XXXXXXXXXXXX or Dr Anna Jones Principal Supervisor Address Tel XXX XXXXXXXX

**Thank you for your time.**

## Statement of Parent Consent

Please read this form carefully. You already have your own copy of pages 1-4. If you have any further questions, do ask. You have the right to change your mind at any time, including after you have signed this form

Title of Project : Predicting Sitting Discomfort In Children Who Use Special Seating And Other Types Of Positioning Equipment

Please initial each box

I confirm that I have read the information sheet dated .....for the above study, have had the opportunity to ask questions, understanding why the research is being done .

☐

I understand that my child's participation is voluntary and that he/she is free to withdraw at any time by contacting Mrs. A Lyons without giving any reason and without the services my child and I receive or my legal rights being affected

☐

I understand that sections of my child's medical notes may be looked at by a responsible individual from .....  
I give permission for these individuals to have access to my child's records.  
I give permission for .....GP to be notified of their involvement in this research project.

☐

I agree to my child (PRINT NAME ) taking part in the study.

☐

Signature..... Date.....

Name ( PRINT)..... Relationship to child.....

Name of person taking consent.....

Signature..... Date.....

## **APPENDIX 6**

### **INTERPLAY OF FOCUS GROUP DYNAMICS**

Gemma: I sort of move myself to get comfortable

Int: so you move yourself to get to a place you want to be, do you know

What that place is?

Gemma: Yes

Int: can you tell me where it is?

Gemma: the straps won't go on if you're not in the right position  
haven't got them on

Rachel: she will be scared to say it supposed to have them on but you haven't got them on,

Int: why do you not like having them on,

Gemma; uncomfortable to have the straps on

Int: It's not nice being uncomfortable is it

Int: what does it feel like when you are uncomfortable?

Gemma: Well my back hurts the bottom of my back (FG1p.4)

## APPENDIX 7

### FOCUS GROUP SCHEDULE

---

#### Before the children arrive

- Meet moderator / buddy, explain their role
- Ensure obstacles are tidied away to enable positioning of 6 wheelchairs
- Check source of power
- Check all consent forms
- Prepare juice
- Check script

#### Children on arrival

- Introduce myself
- Allow the children to find their own space within semicircle
- Find out the name of each child and place name tent on the wheelchair tray/table close to child
- Give each child the three traffic light circles and explain purpose
- Test the recording device
- Play this back to the children so they can hear their own voice
- Ask if they are happy to go ahead, remind them they don't have to answer question and can leave

Open questions	How long you have been coming to this school? How do you get here? Do you travel in a taxi, or mini-bus
Question	Can we talk about how you got in your wheelchair today? Prompts have you been in the chair all day? How much help did you need to get into the chair?
Pictures of chairs	I have brought some pictures of chairs. Is there anything you would like to say about these chairs?
Question	Since you arrived at school have you asked anyone to help you change your position? Tell me what happened? Who, how often. How many times?
Question	Since you came to school have you changed your own position
Clip art/ pictures of possible painful situations	I have more pictures for us to look at. What can you say about this picture?
Body charts	Has your chair ever made you sore ? Show me

- Closing discussion
- Return visit
- Letter

## APPENDIX 8

### INFORMATION AND CONSENT: PARENTAL AGREEMENT

#### **Title: Predicting Sitting Discomfort In Children Who Use Special Seating And Other Types of Positioning Equipment**

##### Parental Agreement

Child's surname /family name.....

Child's first names.....

Date of birth.....

Age.....

Responsible health professional .....

Job title.....

Male

Female

Special requirements.....

## Information Sheet for Parents/Guardians

---

### **Predicting Sitting Discomfort in Children Who Use Special Seating and Other Types of Positioning Equipment**

I am inviting your child to take part in the above research. My name is Anne Lyons, a chartered physiotherapist and senior lecturer in physiotherapy at Northumbria University and I will be undertaking this study in collaboration with XXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXX. This is a personal study, which I am doing for my doctoral degree at Northumbria University. My director of studies is Dr Anna Jones. I will discuss the study in detail with Dr Jones as it is progressing.

#### **WHAT THIS RESEARCH IS ABOUT?**

My study aims to investigate comfort and discomfort in children who use special seating and other types of positioning equipment

I am interested in:

- The views, experiences and opinions of parents
- Exploring behaviours which may suggest a child is comfortable or uncomfortable when using prescribed equipment.
- The length of time children can comfortably use the prescribed equipment



This study will enable therapeutic and care management plans to be further developed. It is hoped the study will inform everyday practice, particularly for health, educational and social care professionals who already work or intend to work with this group children. It is hoped that by participating in the study you will benefit from the experience and be reassured with knowledge that the achievement of comfortable, supportive and functional seating is perceived as a priority for your child.

### **WHAT WILL BE ASKED OF YOU?**

I would like to find out the information I need in four ways:

- through talking to you
- asking you to keep a daily diary of equipment use within the home
- consent to observe your child during the school day, and to identify the behaviours described by yourself in the interview, on one of these occasions I would like you to be present. This would involve either a morning or afternoon of your time.
- consent to take some video of your child's daily routines that involve use of seating and positioning equipment in the classroom.

If you consent to your child being involved and are willing to take part in the study I would like to interview you, either in your own home or a venue convenient to yourself. The interview will last about 1 hour. I will ask you to talk about your experiences; including the difficulties you have encountered using equipment.

The structured diary will be left with clear instructions and should only take a few minutes to complete. I will ask you to complete this on three occasions.

With your consent, permission to observe and video your child at school will be obtained from the head teacher and I will liaise with the class teacher and yourself in order to identify a convenient date and time for these observations to take place.

### **WHAT WILL HAPPEN WITH THE INFORMATION?**

The interview will be tape-recorded and is confidential. Your name or your child's name will not be used. The information from the structured diary will enable an observational checklist to be developed. This checklist and the video will be used in stage 2 of the research. This stage involves health, educational and social care professionals who work with this group of children viewing the video to make judgements with regard to comfort and discomfort. At the end of the study the interview tape and the structured log diaries will be retained for two years and then destroyed. With your consent a copy of the video will be retained in order to disseminate the findings of the study to educational forums, special interest groups, carer/user groups and to the health, educational and social care professionals who already work or intend to work with .....

### **SHOULD I TAKE PART?**

It is entirely up to you to decide whether to take part in the research. If you decide not to take part, it will not affect the services you receive in any way. If you

do decide to participate, you can stop taking part, at any time if you wish. This will not affect the services you receive in any way.

If you have any questions about the research, please contact Anne Lyons or by telephone XXXXXXXXXXXX

or by writing to:

Anne Lyons  
Address  
or

NHS Intermediary  
Address and telephone number

Dr Anna Jones

Principal Supervisor

Address and telephone number

Thank you for your time.

## Statement of Parent Consent

Please read this form carefully. You already have your own copy of pages 1-5. If you have any further questions, do ask. You have the right to change your mind at any time, including after you have signed this form

**Title of Project:** Predicting Sitting Discomfort in Children Who Use Special Seating and Other Types of Positioning Equipment

**Please initial each box**

**Name of Researcher:** Anne Lyons

I confirm that I have read the information sheet dated .....for the above study and have had the opportunity to ask questions.

..... ☐

I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason and without the services my child and I receive or our legal rights being affected.

☐

I understand that sections of my child's medical notes may be looked at by responsible individuals from XXXXXXXXXXXXXXXXXXXX XXXXXXXXXXXX where it is relevant to my child taking part I give permission for these individuals to have access to my child's records.

..... ☐

I agree that a copy of the video may be retained for the reasons identified in the information sheet

☐

I agree to take part in the study

☐

I agree to my child (PRINT NAME ) taking part in the study.

☐

Name (PRINT).....

Relationship to child.....

Signature.....

Date.....

Name of person taking consent.....

Signature.....

Date.....

## **APPENDIX 9**

### **PREDICTING SITTING DISCOMFORT IN CHILDREN WHO USE SPECIAL SEATING AND OTHER TYPE S OF POSITIONING EQUIPMENT**

#### **INFORMATION SHEET FOR TEACHERS, THERAPISTS AND SUPPORT STAFF**

My name is Anne Lyons, a chartered physiotherapist and senior lecturer in physiotherapy at Northumbria University and I will be undertaking this study in collaboration with XXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXXX.. My director of studies is Dr Anna Jones. I will discuss the study in detail with Dr Jones as it is progressing. The study has received NHS ethical approval from XXXXXXXXXX Local Research Ethics Committee (LREC), the University Ethics Committee and Research & Development approval from XXXXXXXXXX. This is a personal study, which I am doing for my doctoral degree at Northumbria University. My director of studies is Dr Anna Jones. I will discuss the study in detail with Dr Jones as it is progressing.

The family of ..... have given consent for their child to be involved in the above research project. Your professional lead.....has given me permission to approach you with an invitation to also be involved in the research.

#### **WHAT THIS RESEARCH IS ABOUT?**

My study aims to investigate comfort and discomfort in children who use special seating and other types of positioning equipment

I am interested in:

- The views, experiences and opinions of professionals, caregivers and support staff who work with the children on a daily basis
- Exploring the non-verbal behaviours which may suggest the child/children in your care are comfortable or uncomfortable
- Re-positioning time intervals for equipment use

This study will enable therapeutic and care management strategies to be further developed. It is hoped the study will inform everyday practice, particularly for health, educational and social care professionals who work or intend to work with this group children. The results will be disseminated to the professionals from health; education and social care using established in-service training forums and special interest groups.

## **WHAT WILL BE ASKED OF YOU?**

I would like to find out the information I need in four ways:

- Interviewing professionals and carers
- Asking professionals/carers to keep a daily log diary: two days over a one-week period, repeated on two occasions over a six-month period. The daily log will record periods of equipment use for ....., the different types of equipment used, any perceived discomfort and the behaviours suggestive of comfort and discomfort
- Observing.....in the classroom throughout the school day
- Taking some selected video recordings of the positions and equipment used by.....

If you are willing to take part in the study I would like to interview you, at a venue and time convenient to yourself. The interview will last about 45 minutes. I will ask you to talk about your experiences; including the difficulties you have encountered using equipment and the behaviours displayed by .....that could be perceived as an expressions of comfort or discomfort. The structured diary will be left with clear instructions and should only take a few minutes to complete. Telephone contact will be available should you have any queries.

The family have given me consent to observe and use video to record .....using equipment. I would like to do these observations in the classroom during the course of a school day. With your permission, I will liaise with the head teacher, the parents and yourself in order to identify a convenient date and time for the observations/ video to take place.

A stranger in the classroom may be perceived as being disruptive. However, it is the intention that the observation will be unobtrusive with the researcher initially taking on the role of participant observer. This will follow a period of classroom acclimatisation. The participant role will be marginal; however; it should enable relationships to develop with the other children and staff in the classroom.

### **WHAT WILL HAPPEN WITH THE INFORMATION?**

The interview will be tape-recorded and is confidential. Your name, the child's name and details of the school will not be disclosed. The structured log diary used to record the child's behavioural observations together with those of other children will enable an observational checklist to be developed. This checklist and the video will be used in stage 2 of the research. This stage involves the health, educational and social care professionals who work the child viewing the video and making judgements with regard to comfort and discomfort. This will be followed with a second participant observation session. At the end of the study the interview tape and the structured log diaries will be retained for two years and then destroyed. The parents will be asked if a copy of the video can be retained in order to disseminate the findings of the study to educational forums, special interest and carer/user groups.

### **SHOULD I TAKE PART?**

It is entirely up to you to decide whether to take part in the research.. If you do decide to participate, you can stop taking part, at any time if you wish.

If you have any questions about the research, please contact Anne Lyons by telephone (XXXX)

XXX XXXX

or by writing to:

Anne Lyons

Address

or

NHS Intermediary  
Addressor and telephone number

Dr Anna Jones  
Principal Supervisor  
Address and telephone number

Thank you for your time.



## Statement of Consent

Please read this form carefully. You already have your own copy of pages 1-4. If you have any further questions, do ask. You have the right to change your mind at any time, including after you have signed this form

**Title of Project :** Predicting Sitting Discomfort in Children Who Use Special  
Seating and Other Types Of Positioning Equipment

**Please initial each box**

**Name of Researcher:** Anne Lyons

I confirm that I have read the information sheet dated .....for  
the above study and have had the opportunity to ask questions.

☐

I understand that my participation is voluntary and that I am free  
to withdraw at any time, without giving any reason, without

my legal rights being affected.

☐

I agree to take part in the study

☐

**Name (PRINT)**.....

**Signature**.....

**Date**.....

**Name of person taking consent**.....

**Signature**.....

**Date**.....

- 
1. **Opening general questions**
  2. **Opening trigger questions( to get the parents talking about the types of adaptive seating and other types of positioning equipment used by their child... at home...at school)**  
I understand [...] uses [...]; can you tell me how often this is used? How long is it used at any one time? Have you experienced any problems?
  3. **Exploration of equipment use and daily routines**  
Can you describe a typical day with regard to the use of [item of equipment]? How much of a typical day varies? What about the school day? Probe: Time periods, preferred options and reasons.
  4. **Exploration of comfort and discomfort**  
When [...] is using equipment, how do you know your child is happy?  
Do you think [...] is comfortable?  
Can you describe the opposite of this? How often does this happen?  
Probe: can they remember specific incidents.  
How aware do you think other people are of your child's needs (comfort and discomfort states?).  
Is there any item of equipment, accessory, position or activity that you believe causes [...] distress?  
Does your child experience any discomfort when using equipment? Can you describe how your child behaves in this situation?  
What do you believe is the cause of this discomfort? Is this discomfort present immediately? How long?
  5. **What relieves this discomfort?**  
At what point do you respond? Do you know what happens at school? How do you know [...] is comfortable?
  6. **What do you think is acceptable positioning time and how long do you think [...] should stay in this equipment?** Can you remember the longest [...] has remained in the equipment without experiencing discomfort?
  7. **If you could give any advice to a parent in a similar position, what would that be?**
  8. **If you could give advice to professionals who are interested in getting to know and understand your child more, what would it be?**
  9. **Show parents the behaviours checklist.**  
Ask parent to indicate if their son /daughter exhibits any of the behaviours

## APPENDIX 11

### Checklist of Behavioural Expressions extracted from NCCPC(Breau *et al.*, 2002) and PPP (Hunt *et al.*, 2004)

Case:

Date

When [name] is using equipment and appears to be experiencing discomfort do they

Item	Not at All	A little	Quite a lot	A great deal
Moaning, whining, whimpering (fairly soft)				
Crying (moderately loud)				
Screaming/yelling (very loud)				
Specific sound or vocalization for pain, calm, or distress				
Not cooperating, cranky, irritable, unhappy				
Less interaction with others, withdrawn				
Seeks comfort or physical closeness				
Difficult to distract, not able to satisfy or pacify				
Furrowed brow				
Change in eyes, including squinching of eyes, eyes, open wide, eyes frown				
Turn down of mouth, not smiling				
Lips pucker up, tight, pout, or quiver				
Clenches or grinds teeth, chews, thrusts tongue out,				
Not moving, less active, quiet				
Jumping around, agitated fidgety				
Floppy				
Stiff, spastic, tense, rigid				
Gestures to or touches parts of body that hurt				
Protects, favours or guards part of body that hurts				
Flinches or moves body part away, sensitive to touch				
Moves body in specific way to show pain, calm or distress				
Shivering				
Change in colour or pallor				
Sweating or perspiring				
Tears				
Sharp intake of breath, gasping, breath holding				

## APPENDIX 12

### CHARTS USED TO RECORD CLASSROOM OBSERVATIONS

Date:

Case:

Time	1	2	3	4	5	6
------	---	---	---	---	---	---

9.00						
------	--	--	--	--	--	--

9.15						
------	--	--	--	--	--	--

9.30.						
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9.45						
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10.00						
-------	--	--	--	--	--	--

10.15						
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10.30						
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10.45.						
--------	--	--	--	--	--	--

11.00						
-------	--	--	--	--	--	--

11.15						
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11.30.						
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11.45						
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12.00						
-------	--	--	--	--	--	--

12.15						
-------	--	--	--	--	--	--

#### Column 1: Overall

- 0=Little expression
- 1=Appears happy and calm
- 2=Irritable
- 3=Difficult to pacify

#### Column 2: Mobility within posture

- 1=Stable
- 2=Movements largely within base
- 3=Gross movements outside base
- 4=Movement of Base

#### Column 3: Facial Expression

- 1=Happy smile
- 2=Piercing .sharp glare
- 3=Facial contortion
- 4=Eyes Closed
- 5=Other

#### Column 4: Vocal Expression

- 0= No vocal expression
- 1=Loud yells, grunts or shouts
- 2=happy giggles or gurgles
- 3=Screaming
- 4=Word

#### Column 5: Limb movement

- 1= Large flinging limb movement
- 2=In mouth, repetitive, small range limb movements
- 3= Hitting other parts of body
- 4=Stiff
- 5=Spasms
- 6= Purposeful

#### Column 6: Activity

- 1=Curriculum individual
- 2=Curriculum group
- 3=Transfer
- 4=Food/drink
- 5=Personal Hygiene
- 6= No directed activity
- 7=Therapy
- 8= Care

12.30.							
--------	--	--	--	--	--	--	--

12.45							
-------	--	--	--	--	--	--	--

1.00							
------	--	--	--	--	--	--	--

1.15							
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1.30.							
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1.45							
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2.00							
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2.15							
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2.30							
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2.45							
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3.00							
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3.15							
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3.30							
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3.45.							
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4.00							
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## Appendix 12 (B) EQUIPMENT AND ACTIVITIES

S	Sitting	W	Wheelchair	SP	Stable posture	H( F or UF)	Harness
A	Adaptive seating	CC	Classroom unadapted chair	F	Fastened	SB (F or UF)	Seat belt
ST	Standing	P	Person	UF	Fastened	FS	Footstrap
L	Lying	F	Free	C	Classroom	USP	Unstable posture
SL	Sidelying	Te	Teacher	Ta	Teaching assistant	Te	Therapist

	Type of activity	Time	Type of equipment	Position	Posture managed	Accessories U=used Un=Unused	Free	Independently achieved	Staff facilitated	Staff and equipment facilitated
Arrival										
Registration										
<b>Curriculum class group engagement</b>										
<b>Curriculum individual engagement</b>										
<b>Curriculum school engagement</b>										
Snack										
Clean up										
Bathroom										
Free play										
Lunch										
Post -lunch										
Therapy										
Snack										
Other										
Departure										

## APPENDIX 13

### Member Checking

#### An Exploration of Comfort and Discomfort in Children and Young People who use Special (Adaptive) Seating and Postural Management Equipment

#### STILL IMAGES

Thank you for your help with this study. I am going to show you a number of still facial images. For each image, please select one of the categories.

	At ease	Engaged and content	Very happy	Expectation	Dislike	Becoming distressed and agitated	Distressed
1							
2							
3							
4							
5							
6							

Which facial features help you make this decision?

	Brow	Eyes	Mouth	Lips	Teeth, tongue
1					
2					
3					
4					
5					
6					

## APPENDIX 13

### Comfort and Discomfort (Adapted from Kolcaba, 2003)

Thank you for your help with this study. There will be a number of video clips of different length for you to view. Below are statements that may describe your views of the different postures, positions and equipment. Six numbers are provided for each statement; after each clip please circle the number you think most closely matches your feeling.

Strongly disagree

Strongly agree

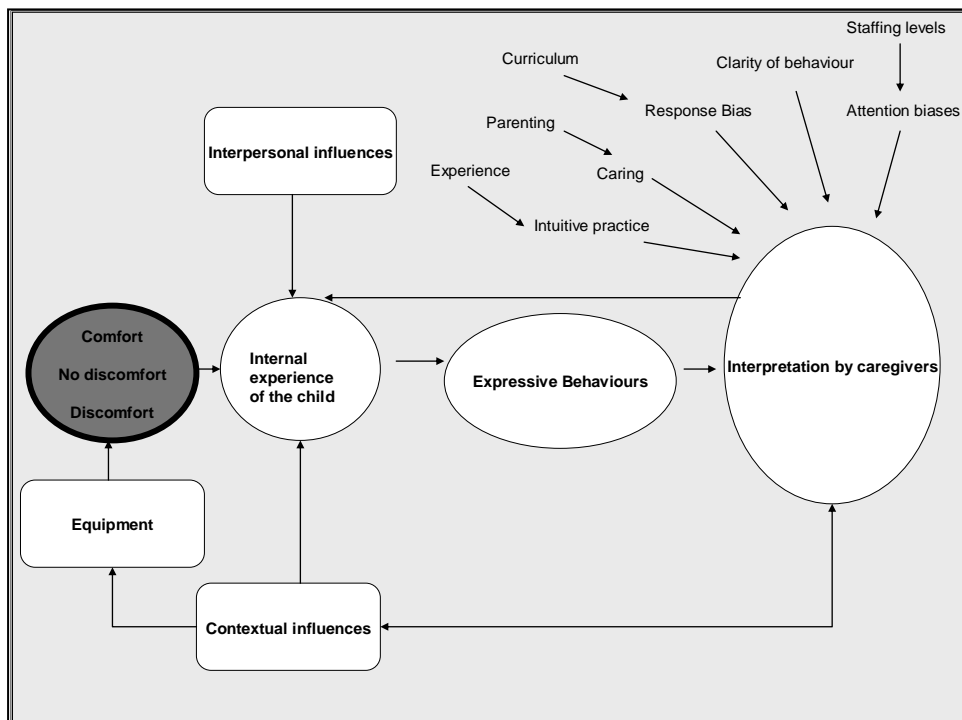
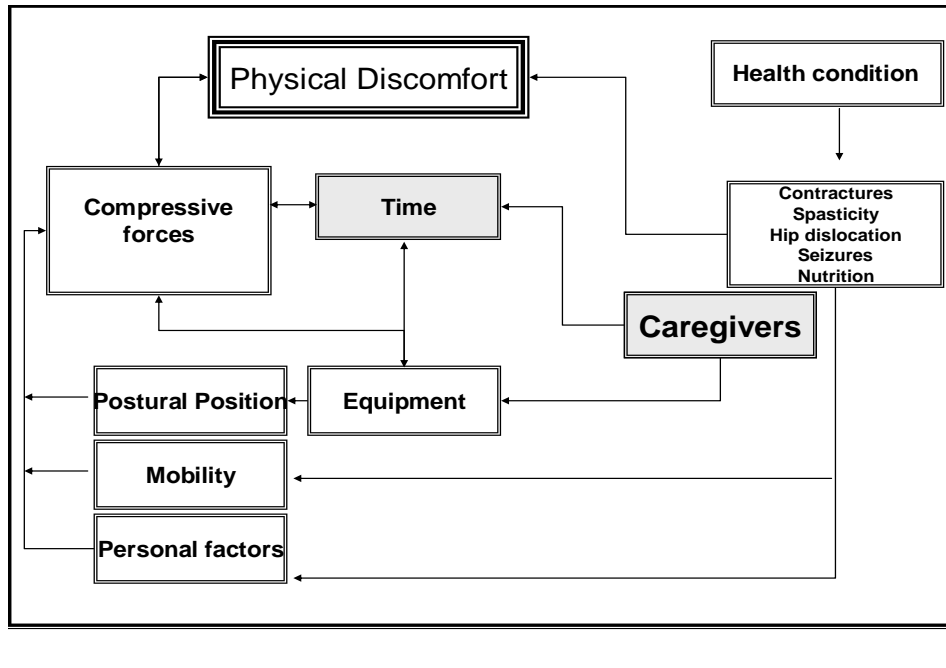
<b>1</b>	<b>His or her body is relaxed right now</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>
<b>2</b>	<b>It will be difficult for him/her to function from this position.</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>
<b>3</b>	<b>He/she looks uncomfortable</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>
<b>4</b>	<b>He /she is communicating right now</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>
<b>5</b>	<b>He /she look scared/panicky</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>
<b>6</b>	<b>The look is that of expectation: of an activity/social interaction</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>
<b>7</b>	<b>The chair/equipment looks as though it is hurting him/her</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>
<b>8</b>	<b>There are those in the vicinity he /she can depend on</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>
<b>9</b>	<b>He/she looks content and at ease with their surroundings</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>
<b>10</b>	<b>He /she looks as though they like this</b>	<b>1</b>	<b>2</b>	<b>3</b>	<b>4</b>	<b>5</b>	<b>6</b>



11	<b>He/she is cooperating with staff</b>	1	2	3	4	5	6
12	<b>I need to adjust his/her posture now</b>	1	2	3	4	5	6
13	<b>He/she is engaging in social/curriculum activity</b>	1	2	3	4	5	6
14	<b>He/she is distressed</b>	1	2	3	4	5	6
15	<b>He/she looks comfortable</b>	1	2	3	4	5	6
16	<b>He/she looks well supported right now and can function well from this position.</b>	1	2	3	4	5	6
17	<b>His /her moaning/ groaning /crying indicate to me they are not happy</b>	1	2	3	4	5	6
18	<b>This postural position is poor and will not be tolerated much longer</b>	1	2	3	4	5	6
19	<b>This posture is typical for him / her, and I know he/she is happy to stay in this position for at least 1-2 hours without signs of distress.</b>	1	2	3	4	5	6
20	<b>His/her facial expression indicates they are not happy</b>	1	2	3	4	5	6
21	<b>He/she is restless</b>	1	2	3	4	5	6
22	<b>I know his/her position can be improved</b>	1	2	3	4	5	6

## APPENDIX 14

### ATTRIBUTES OF PHYSICAL DISCOMFORT



## APPENDIX 15

**Table displays: Behaviours (shaded lines–unhappy emotional expressions)**

Case	Parent	Education Staff Key worker staff	Therapy Staff
1	Smiling, fingers in her mouth, happy sounds. Sometimes, it's as though she sings, constant tone and that sort of contentment when she's happy.	She smiles, lots of smiles and lots of giggles and I know that she's happy. She moves around all the time, her arms and legs just move and she doesn't really have much control over them, but they move in a different way when she's happy, she's a lot more bubbly and kind of bouncy so her arms and legs moving and jerking. Always accompanied with kind of giggles and smiles and just by looking at her face you know she's happy. And her eyes, they're quite bright and alert, a kind of turquoise bright blue	Expression of her contentment , happiness Just the look of her she is stiller And she does smile I think she is actually just still, not thrashing around, less vocal.
1	If she is on the floor and she is in a paddy, she will sort of bang her feet. Like with her feet, and that, you know; just total, you can just tell the way she is, she looks upset And when she is really upset, her face is red. Actually, pulling faces. It's like crying	Her eyes can be quite dark and she can, she doesn't often cry. She'll do a bit of crying, but that's not a long drawn out process it can go from a few whimpers to follow on screaming and a big paddy within the space of a minute. She rather screws her face up like a grimace type thing. She shakes her head from side to side .If she's doing an activity and she's not too keen she'll pull her hands away and she'll kind of make noises as if to say 'I don't want to do that, but eyes change and they go dark	She is very vocal when she is not happy When agitated, she flings herself about more, wriggles more, she vocalises more.
2	She's nearly always happy; you worry when she's not happy. It's not that's she's always smiling ...I just don't know you can tell she is happy	it's because you know the child, if you see her happy, It's like a glee, she rocks herself, self stimulation, she rocks, her hand, she rocks her head, and she watches you when she is happy she can be very affectionate, she pulls at you, she is happy as can be	She waves her head a little bit and she smiles, her face is more animated. When she is quite happy she lifts her arms like a rangy doll and waves them and waggles her head yes, but nothing great it's just a little movement- it's quite subtle
2	Frustration. She cries. She bites her hand A scream and bite her hands, she would bite anything. She would kick her feet and she just, it's as if she's just throwing herself around because there's something, you don't know what, something's not right	She will bite her hand, she will bang, she will be distressed, and you can see the way she wriggles. If she's distressed with anything she is doing, you get the hand biting, the hand right back in the mouth, throwing, hitting out. It is very clear if she does not like something.	If she doesn't want to stand or play with something, she will just push it away. I can't say I have ever heard Katie cry or show any discomfort No, she always appears to be a placid, quite happy little girl. It is how everyone would see her as a happy girl

	Parent	Education/ Key worker	Therapy
3	He also bites his hand when he is happy, so	Because he laughs, he smiles, chatty.	His facial expression
3	He bites his hand out of frustration, he shouts, he screams more. Loud. He will point to where it is	I think it's just because you know him and you can tell by the impression on his face. I mean he does cry but then he can cry quite easily, you know. I mean I wouldn't take that as a massive indicator because if anybody speaks to him sharply there's a flood of tears	His facial expression, a few tears. I think he can make himself understood, if he is not comfortable, he will not just sit there, he'll do something, he will either moan or point
4	Her thumb and her forefinger can express both happiness and that she is not too suited	I think we can tell by... a lot by her movements, if she's happy, if she's content she's still, Therefore, of a cooing she smiles. She has a calming look on her face	She smiles, giggles and make noises, yes she gets a smile on her face and a little look, it's like a little, you know, you look and think oh she's enjoying that
4	You put her toys there and she is not interested, her right hand she just seems to wave it incessantly. When she has the concentration on something, it is intense. She will pull away or push away from you, but not cry. It is her whole facial expression. It is difficult to describe You cannot put your finger on it, but she is she is not suited in her face	if she's not happy her hands go, her head go and sometimes flushes up, totally different movements, they're quicker	I've never seen her cry with anything really, even when she gets quite upset. If she's unhappy or something she claps her hand, she bangs her right hand and it gets faster and faster the more agitated she gets, then she gets really cross the finger comes out Sometimes if she doesn't want to do it, she'll give you a slow pat, if your causing her some discomfort she'll slap harder, she'll bang harder so you can tell from the intensity and the speed
5	when she is quite happy or she will give a little squeal, a happy squeal and bring her arms and legs up	She laughs She shouts out. She vocalizes. She might have a little scream, she shouts out, If she is fine, her head will lift up, her eyes will light up, a big smile, and then you know it is a yes. We know they she is happy.	She smiles and she keeps her head up and she'll make noises. She'll actually project her voice. She'll shout at you and giggle.
	She'll do that sort of twisty sound .If she's uncomfortable she'll do that sort of noise there like a little cry or whimper and that means something's wrong. She still has a pet lip, she's always done that and if she's got tears or anything it's a proper cry you know something more serious	Sticking her tongue out she lets you know she doesn't want something.	She'll cry, cry, and cry, real sobbing heart-rending cries. Yes, very, very upset. Sobs and intakes of breath, the lot, it a full upset, yeah. She'll nod her head, she'll stick her tongue out

	Parent	Education/ Key worker	Therapy
6	She laughs and she giggles and she chats and she dances on the floor, the head rocks, she is a good little head rocker and the head goes round and round in circles, she dances, laughing and giggling, you can tell if she is happy. She has got a really happy nature. She has her moments, don't get me wrong but she has a nice nature you would just know, by her whole attitude	Chats	happiest sitting in a group of people chattering smiling and she's quiet, she's not moaning
6	I wouldn't say it is eyes or mouth. It is sort of here, this face, here, sort of changes. I am not going to say deathly white but she just changes colour a little, yes I just know, not even in pain. I just know when there is something not right. A real whale	She can look a bit flushed or just look tired or become I would probably say less chatty or... and then if you do ask her? She'd reply straightaway 'yes' she will become very uncooperative and shouting	She moans She never mentions it being painful, hurtful or it's too tight. It's always I don't want to do this If you want to stretch, she certainly lets you know that it hurts but I don't think she uses the word hurt
7	You can tell by his facial expression, the way he is laughing.	He smiles and he giggles	He smiles, he laughs, his face is lifted, you can tell. He is very much more vocal when he is happy, he sings Again, because he looks happy, he is smiling, he has his head up, and he is taking notice. His arms are relaxed, generally, his posture is relaxed, and he'll start giggling or laughing He will turn toward you sometime. On a good day you will get a response, a facial response as if he is listening, his head, he will lift his head up. They are the only sought of responses. They are quite subtle as well unless you know him quite well you might miss that little turn he is actually engaging with you. We do a lot of work on the front with him, on the side. Yes, you can see a response
7	Crying. He has never had tears, even if you poked him in the eye, he doesn't have tears. Blotchy loud screaming	He kind of moans a bit to start. So then he cries and once he's uncomfortable and he's a bit fidgety and a whiney and then he's crying you've lost interest he had in the activities.	If he is not happy, his brow comes down and he scowls. Facial expression you can see by his face he is not happy, it is a very unhappy little face

	Parent	Education/Key worker	Therapy
8	His face when he can move around freely , a smile	He vocalizes. His whole demeanour is just so much more happier	Wandering around at home. He is always extremely happy, he has a nice smile on his face I think I only seen him distressed a couple of times I think when the seizure activity was very high. He is quite placid in lots of ways. I don't think I have actually seen him cry.
8	He rarely expresses pain, in terms of crying a frightened rabbit look on his face. Usually quivering, but often very little noise. With severe pain only a whimper. He may flinch a little. He gets agitated if he is not moving	He doesn't shriek, he doesn't shout. He just becomes very, very passive, more passive, he doesn't reach out. He tries to go to sleep. .He just sort of.....more if you like. The only time when you try to give him a drink and he doesn't like that sort of pulls back and grimaces	I think I only seen him distressed a couple of times I think when the seizure activity was very high. He is quite placid in lots of ways. I don't think I have actually seen him cry.
9	The eyes, the mouth, especially the eyes. You know how you say you see someone smiling with his or her eyes. Ellie does that	Massive smiles. She speaks with her eyes, you can read the expression, and you can see the mischievous look when she is doing something she enjoys. She is really smiley isn't she, she does laugh at things as well. You definitely know when she is not happy.	She smiles
9	The facial expression, she pulls and twists her mouth Horror in her face. You can tell by the expressions in her face. She pulls these certain faces when she is not happy and it's not teary eyes and things like that. It's the twisting of the mouth as she's concentrating to move out of a position. The expression in her face is the same one every time. She pulls; she twists her mouth when she's not comfortable and not happy. Definite moaning and groaning. She'll like whinge at you or until you do something to move her or take her out of the seat if she doesn't want to be in or the straps are too tight. She pushes with her hips if it is the one around the hip area. She twists to the side and the she tries to slide out of the seat and we know she's had enough when she's trying to get out.	Her facial expressions, she will cry for one and twisting of her face. She lashes out a bit, she will arch her back .Her legs will stiffen if she doesn't want to go in the equipment	She flings herself, extensor spasms
	Parent	Education/ Key worker	Therapy
10	Oh he just glares, he just smiles at you.	It is harder to read his expression, but he is able to let us know he is enjoying something, he smiles and giggles	I think his face his mouth, he lifts his head up and he is looking at you.

10	He whines if you don't go to him and then he cries but he just whines at first we have learnt his different whines. There's a whine when he's like bored and there's a whine when he's generally upset and then he has like his proper crying. His face doesn't look right but it's just like a grimace. Yeah, aha and sometimes he'll put his eyes right up. He tenses up, yeah and he just scratches at the back of his head	He cries. When he is really upset he does, he just sort of pulls a face. He moves his head out of the way. When he is really upset he does, he just sort of pulls a face.....	The cry, the sobbing? He gets quite distressed. He can get grizzly and miserable if he doesn't particularly want to be doing what you want to be doing with him, a lot of crying, and a whale. It is quite different He had his hands to mouth more which he seems to do when he is upset, his expression, a growl, a scowl mouth crumpled, sort of very pale
11	I mean if you were sitting here and he was quite happy with you he would have a hold of your hand and he'd be kissing it all the time.	Smiles, more vocal, interacts more	When you do get him quite happy it's a good day and you can do loads with him but when he's in a bit of a mood you can't do anything with him, he just becomes quite passive
11	Changing noise including squinting of eyes, eyes open' Yes, does, turn down twist of mouth' not smiling, head down. His lips pucker up when he's going to have tears, which isn't very often mind. Then the huffing You can tell he's agitated You get this huffing and puffing and there's no doubting that he's not happy with something. Lately if he's been maybe in a bit pain what he'll do as well, he'll get hold of your hand and puts it on his head.	Rus his head with hands if he is not enjoying or uncomfortable. Crunchy eyes, turns away, pants, shouts	When he's not very happy he'll start to pant and blow he purses his lips and makes that noise. You tend to know with Phillip, if he tends not want to do something or he's uncomfortable or something is hurting him he'll grab you and push you away.

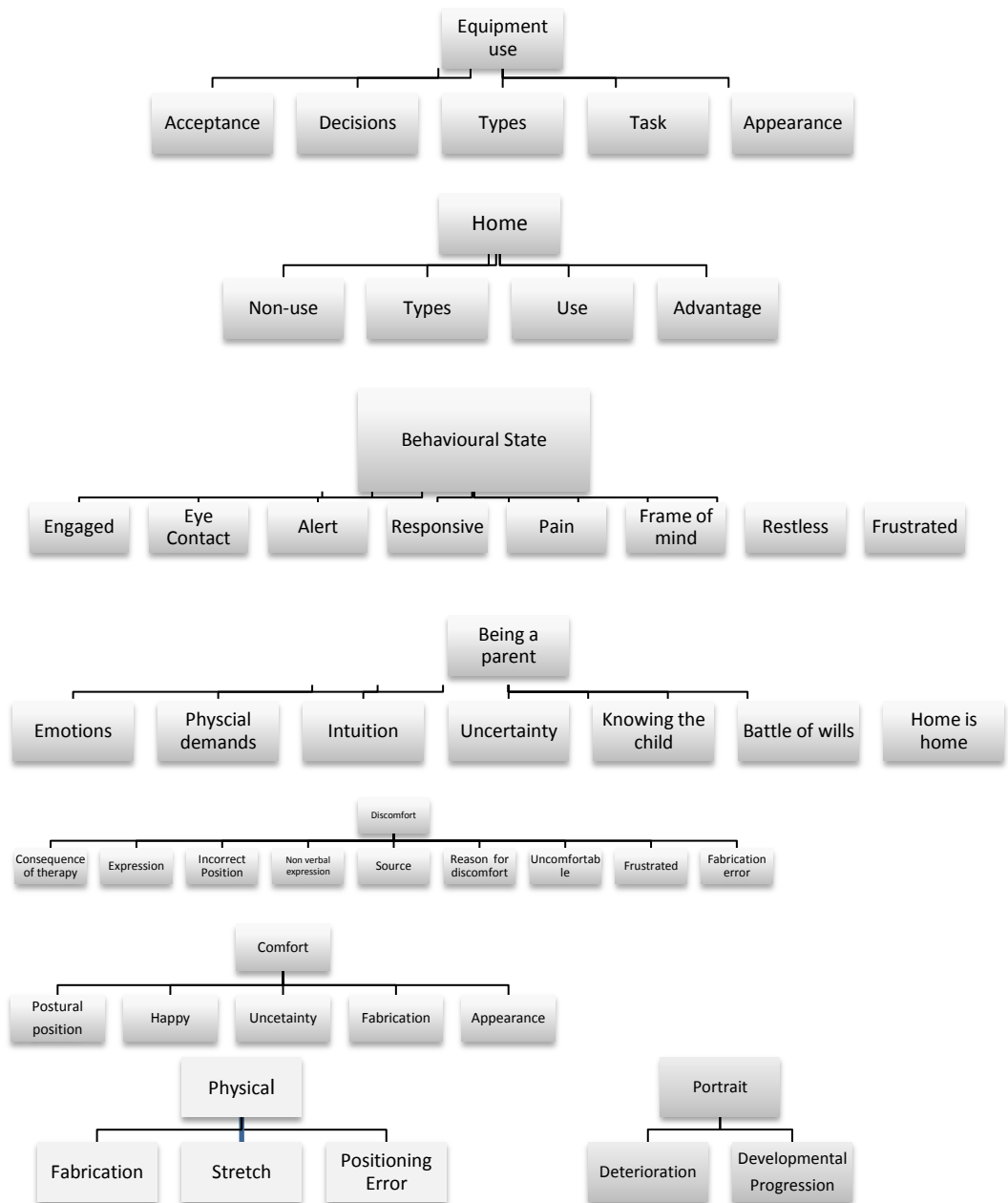
	Parent	Education/ Key worker	Therapy
12	When she's very, very happy and you say there's a smile that she's got there. She definitely has different sounds That's her happy smiling, that's what she's like in her chair	She laughs, smiles and takes more notice of the environment. Higher pitch vocalisation	Her eyes are quite sparked, she gets quite sparkly eyes, her eyes are quite taking everything in and she's got this really big smile on her face and all you can get is a giggle.
12	But when she's not happy she's like sort of ... she'll rub her eyes or she'll move around a bit, you know, and she'll go like this or she'll ..... I don't know, you can just tell with her you know she makes some funny noises, completely different noises, she's has different noises for different things. If she's not well I know she's not well because she makes like a really sad noise.	She will bite her right hand when she is not happy. Grip out at people nearby if she is not happy She will then start to cry. She looks unhappy, frowns, rubs eyes and goes rigid	It's quite hard to sort of explain because you know someone's little quirks and you can tell if someone is not very happy, like Vikki, if she's not happy with something she will cry, she does cry. Oh yes, it's a cry like sobbing, like quite a distressful cry. Her lips sort of go as well, she sort of gets a little quiver and then you know the tears are start. You'll get more with the hand and she'll bite as well. I

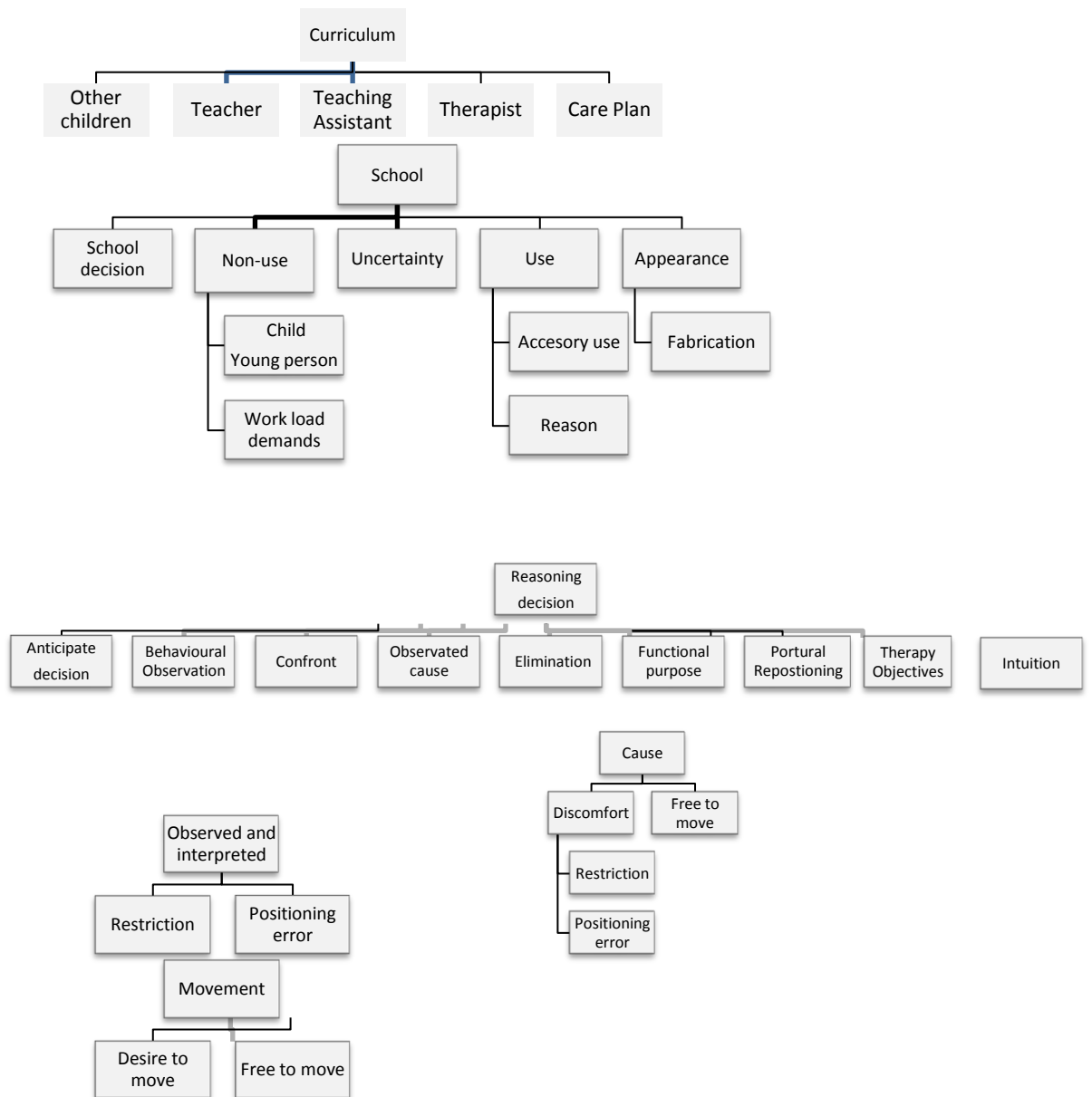
			say she'll sort of get a bit of a grimace and she'll get a little bit pouting, like pouting, quivering of the lips a little bit, not be very happy.
13	Smile, laugh, happy squeal	Smiling, you can tell by his eyes, his eyes brighten smiling and laughing Laughs and giggles	Laughs, smiles, giggles, interacts. He can squeal with delight
13	If pain he will cry for ages, sweats quite a lot stiffen and shout at you. Will scratch the back of his head if he is unwell. Whole face expression Unhappy frown	Different vocalizations and also, the colour drains out on him. He goes a funny colour we have just recently kind of noticed that when he is unhappy. His eyes, I would say a colour change in his skin pause. Moans and groans, but I don't think I have ever seen him cry. No tears	He is not passive. He will start to shout and he will moan and groan until somebody comes to sort him out Facial expression , lots of vocalisation and he is trying to thrust his pelvis forward and you know his bottom his not far enough back, he will just be very agitated, and he will cry some times Vocalisation, he will start to whinge and cry and will then try and make something happen. He tries to extend. He knows enough to kick off and he will go into extension and fling himself around It is like a build up. You start to get the moaning groaning, then the facial and then build up absolute screaming.



## APPENDIX 16

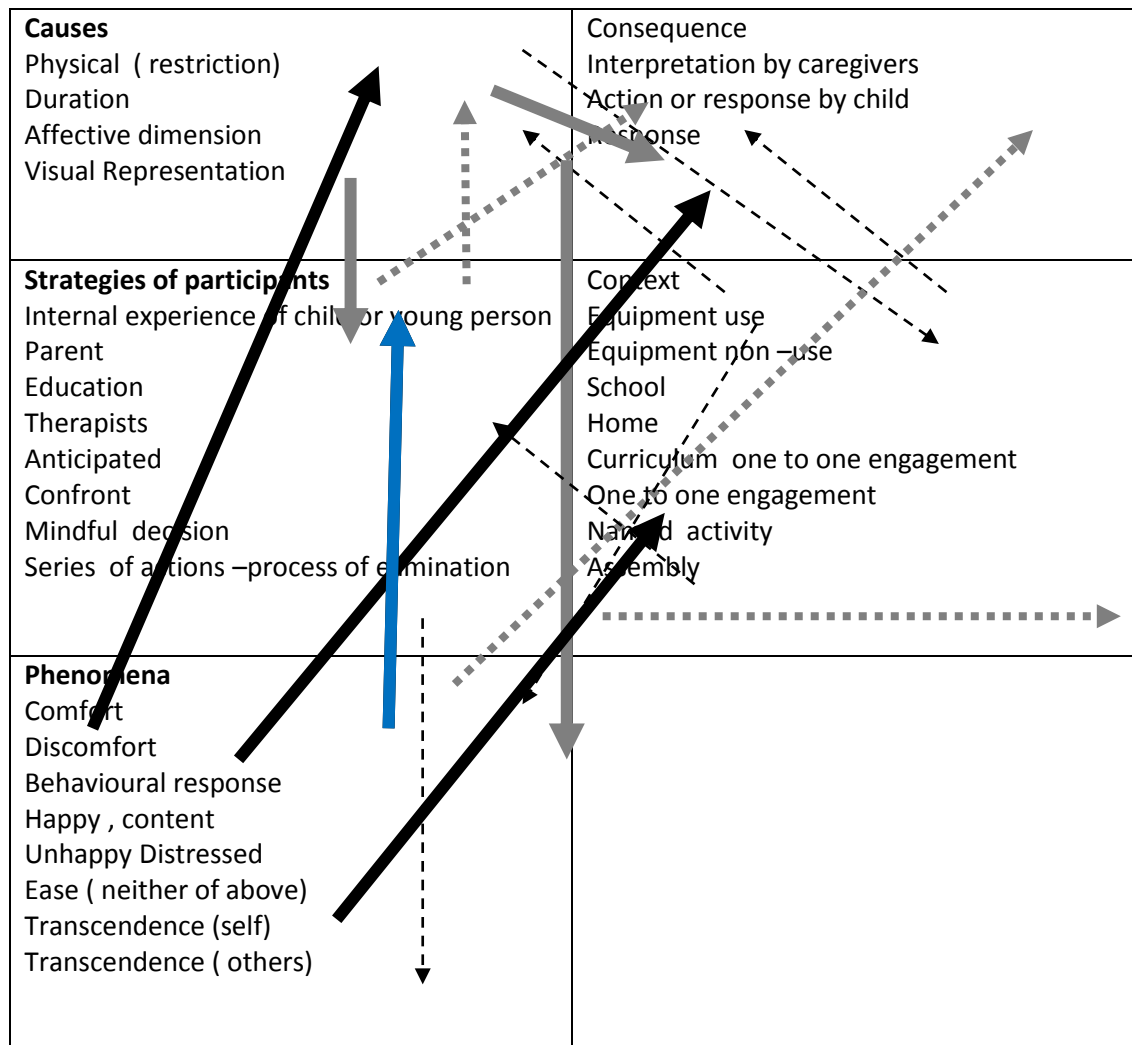
### Family Nodes





## APPENDIX 17

## EXAMINATION OF RELATIONSHIPS WITH DATA



## APPENDIX 18

### NOTATIONS

Cases numbered 1-13

P=parent

T=therapist

Te=teacher

Ta= teaching assistant

KW= key worker

i=interview followed by number, then page number for example 3i1:7 = interview 1  
page 7 for case 3

V= video

O= observation

FN= field note

FN=followed by I, O V

FG=Focus Group

Int=interviewer

[ ] clarification

... gap in data

## APPENDIX 19

### CHECKLIST OF BEHAVIOURAL EXPRESSIONS FROM SINGLE CASE (13)

When [name] is using equipment and appears to be experiencing discomfort do they

Item	Not at All	A little	Quite a lot	A great deal
Moaning, whining, whimpering (fairly soft)	Te	P	T,	
Crying (moderately loud)			P, T, Te	
Screaming/yelling (very loud)		T	P, Te	
Specific sound or vocalization for pain, calm, or distress		T	P Te	T
Not cooperating, cranky, irritable, unhappy		T, P	Te	
Less interaction with others, withdrawn	P, Te		P	
Seeks comfort or physical closeness		T		P, Te
Difficult to distract, not able to satisfy or pacify	Te, P	T,		
Furrowed brow	T	Te	Te	P
Change in eyes, including squinching of eyes, eyes, open wide, eyes frown			T Te	P
Turn down of mouth, not smiling			P, T, Te	
Lips pucker up, tight, pout, or quiver	Te, P		T	
Clenches or grinds teeth, chews, thrusts tongue out,	Te, T		P	
Not moving, less active, quiet	Te, T, P			
Jumping around, agitated fidgety	Te, P		T	
Floppy	Te, T			P
Stiff, spastic, tense, rigid			Te	P T
Gestures to or touches parts of body that hurt	Te, T, P			
Protects, favours or guards part of body that hurts	Te, T, P			
Flinches or moves body part away, sensitive to touch	T,P			
Moves body in specific way to show pain, calm or distress	Te	P	T	
Shivering	Te T			P
Change in colour or pallor		Te, T,P		
Sweating or perspiring		T	Te	P
Tears	Te	T		
Sharp intake of breath, gasping, breath holding	Te T, ,P			P

(Te= Teacher, T=therapist, P=parent)

## APPENDIX 20

### CHECKLIST OF BEHAVIOURAL EXPRESSIONS

Item	Not at All	A little	Quite a lot	A great deal
Moaning, whining, whimpering (fairly soft)	4	1,2,5,8 9, 11	3,10,7,12,13,	7
Crying (moderately loud)	2,4,11,12	1,3,19,	5,10,13	7
Screaming/yelling (very loud)	4,7,10,11,12,	1,5,9,13	3,7,	
Specific sound or vocalization for pain, calm, or distress	12	9	1,5,7,10,11	3,13
Not cooperating, cranky, irritable, unhappy	9,	1,2,3,4,9,12,13	5,7,10,11	7
Less interaction with others, withdrawn	1,9,13	2,3,4,5,10,12	,11	7
Seeks comfort or physical closeness	4,11,12	7,8,10,13	3,5,11,	1,9
Difficult to distract, not able to satisfy or pacify, hard to console or comfort	11,	1, 3,8,12,13	5,7,9,10,	7
Furrowed brow	4,	1,2, 3 5, 12,13	9,7,11,	7
Change in eyes, including squinching of eyes, eyes, <u>open wide</u> , eyes frown	12	3,4,5,10,12,13	1,2,9,7,8,11	
Turn down of mouth, not smiling	1,4,	5,3,13	9,7,10,11,12	
Lips pucker up, tight, pout, or quiver	1,4,	2,3,5,8,10,11, 13	7,1	7
Clenches or grinds teeth, chews, thrusts tongue out,	3,4,8,11,12,13	1,5,10	7,9,	
Not moving, less active, quiet	3,5,8,9,12,13	1,4,11	7, 10, ,	
Jumping around, agitated fidgety	1,4 ,5,2,3	1,8	7,9, 10,11,13,	
Floppy	4,5,8,9,11,12,3	1		7,10
Stiff, spastic, tense, rigid	4,7,8,=,10	11,12,3	1,5,13	7,9
Gestures to or touches parts of body that hurt	14,5,7,8,10,12,13	11		3
Protects, favours or guards part of body that hurts. Rubs	14,5,7,8,9, 10,11,13	12		3
Flinches or moves body part away, sensitive to touch	8,12,13	4,5,7,10,11	9	3
Moves body in specific way to show pain, calm or distress,	5,7,8,12	1,10,4,	2,9,11,13	3
Shivering	1,3,4,7,8,9,10,11,12,13	5		7
Change in colour or pallor	1,11,7,8,10,11	4,5,9,12,13		3
Sweating or perspiring	3,7,8,9, 10,11,12,	4,5,13	1	
Tears	4,11	1,9,3,13	1,2,4,,7 10,	7